Caring Together

The Report of the Expert
Working Group on
Integrated Palliative Care
for Persons with AIDS
to Health and Welfare Canada
Federal Centre for AIDS

February 1989

Canada

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Également disponible en français sous le titre "Au nom des nôtres"

©Minister of Supply and Services Canada 1989
Cat. No. H43-53/2-1989 E
ISBN 0-662-16880-1

89-05563/

"I must here take further notice that nothing was more fatal to the inhabitants of this city than the supine negligence of the people themselves, who, during the long notice or warning of the visitation, made no provision for it...."

from Daniel Defoe's account of the ***Plague of 1665*** *contained in A Journal of the Plague Year, published in 1722.*

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The Challenge of AIDS

The preparation of this document and the examination of a subject as sensitive as Acquired Immunodeficiency Syndrome (AIDS) was an extremely valuable experience for each and every member of the Working Group. We attempted to move beyond our own prejudices and beyond the myths and taboos spread by public opinion, the media, politicians and even by scientists. We committed ourselves to looking at a human being stricken by a lethal viral infection, a human being with specific needs to which we must respond. After much painful deliberation, we now feel ready to submit our recommendations.

Nature of the Disease

Biologically, AIDS represents the most recent and severe manifestations of infection attacking the human species. The culprit is a retrovirus called Human Immunodeficiency Virus (HIV). Since 1983, research has shown that HIV is a transmissible infection, mainly attacking the integrity of the immune system. International data clearly demonstrate that the virus can strike anyone.

In the Western world, AIDS to date has affected mainly adult males in the prime of life. In our consumer-oriented society, it is during this period of life that individuals are beginning to benefit from the rewards of hard work. As a result, AIDS becomes a personal disaster, whereby career and life goals are shattered. The serious interpersonal and family repercussions also create social disruption. Those in the person's immediate circle are unable to really understand what is happening and thus react negatively, their reason clouded by emotion. This aspect is the social dimension of AIDS.

The third aspect of AIDS, the societal dimension, is a phenomenon which has left a significant mark on the social fabric of our society. To find another infectious event with similar societal implications, we need to look back several decades to the polio epidemic of the 1950s or the Spanish flu of 1918. Again, three age-old fears have been reawakened: the fear that medicine is powerless in the face of a new disease, the fear of suffering and the fear of death. Furthermore, modern technology has rapidly transformed AIDS into a "media disease" with its sensational aspects being exploited by the news--sex and death are both involved. All these combined ingredients have created a major disruption of society.

AIDS is, therefore, **a disease with three dimensions -- biological, social and societal** -- *and any health care strategy must address all three components* in addition to the needs of persons with AIDS and their families, and the required services from the time of diagnosis until death.

A Developing Phenomenon

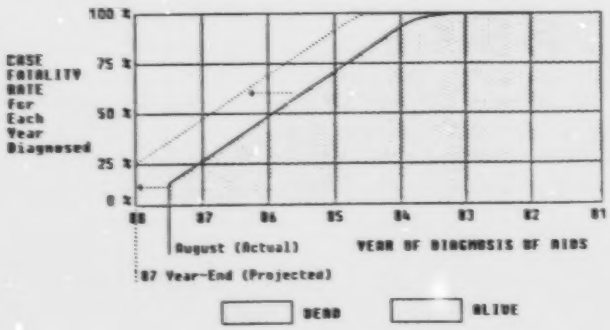
AIDS has become a part of our society, as shown by the cumulative total of cases recorded in Canada (Appendix I). An international perspective demonstrates definite variations in the number of cases noted. In Central Africa, "the situation is so catastrophic that it is going to reach a point of no return."[1] In North America and Europe, the virus is beginning to spread, while in Asia it is only recently evident. Conclusion: the virus spreads slowly, but surely.

Significantly, the virus itself is variable in structure and a new strain has been discovered in West Africa (HIV-2). The cumulative number of cases is growing and will continue to increase, with more equal distribution with respect to age, sex, geography and means of transmission. We also know that with the advent of new diagnostic tests and experimental therapeutic agents, the interval between diagnosis and death will lengthen. Therefore, we will have to think of AIDS more in terms

[1] F. Barre-Sinoussi, J.C. Chermann and W. Rozenbaum, Ed. P. Lon, *Le SIDA en questions*, city, country: 1987.

of a chronic disease interspersed with acute episodes, keeping in mind that AIDS remains an inevitably fatal disease, as the fatality rate curve[2] in Figure 1 illustrates.

Figure 1: AIDS Deaths



Predicting and Preparing for the Future

AIDS represents a massive challenge to our health care and social service systems. We must learn or relearn to develop the capacity to anticipate change with respect to the needs and realities of the disease. Existing structures must be adaptable and flexible, not only to meet the needs of AIDS patients competently, but more importantly to meet those needs in a timely fashion. The Working Group's findings demonstrate that, in many parts of Canada, health care and social services, volunteer and community groups are presently overburdened and incapable of adequately meeting current needs. These organizations and groups will be totally unable to provide the number of quality services required in the near future.

Canada boasts about its health care system with its universal access to care. Given our already burdened services and the moral and ethical reactions to this disease, AIDS forces us to examine the sincerity of our intentions and ask to what extent we are committed to maintaining human integrity.

Death and Dying

The community at large, scientists, health officials, caregivers -- all must cease to consider death as a failure. In fact, a "quality death" at the end of life is not a failure but a great success, a part of the continuum between birth and death. People working with the aged, cancer patients and the terminally ill have learned this truth and have demystified their own deaths as a result. This perception, unfortunately, does not belong to those who decide to prolong life at any cost, or those who refuse to accept mortality.

Although a diagnosis of AIDS means biological death in the near future, it also immediately signifies psychological and emotional death for those affected -- men, women and, we must not forget, children. A diagnosis of AIDS is comparable to being given a death sentence and often leads to hopelessness and despair in those individuals infected with the virus. Our society and health care system do not yet universally accept that it is necessary to deal with these different needs which, if left unattended, lead to a devastating death. Our health care and social service systems must now focus their energies on informing, educating and promoting respect for this process.

Palliative Care

It is clear to us that all the principles underlying palliative care apply to AIDS, in particular the right to make choices, including the right to change one's mind and the right to be respected as a valuable, productive, emotional and sensual human being. However, AIDS demands even more from us, since our society has consistently attributed such a negative value to this

[2]Compiled from *Update: AIDS in Canada*, Laboratory Centre for Disease Control, Ottawa, August 4, 1987.

disease. Furthermore, great effort is made to continue to maintain and support this negativism, as if to be on the side of good. Even the caregiving team, whether providing physical or emotional care, is not impervious to these none-too-subtle pejorative messages. Awareness of this negativism is the first step toward resolution of the problem.

The Positive Aspect of AIDS

Within AIDS lies the potential for positive change in our society, for profound and far-reaching effects on health care and social services. Compassion, multidisciplinary cooperation, volunteerism, self-help and selflessness -- AIDS could be the catalyst for these individual and collective values. We believe these values are the positive and achievable aspects of AIDS, provided we are able to rise above our own prejudices, fears, value judgments and personal anxieties.

A New Problem, New Solutions

AIDS is a new disease calling for new approaches, and we are convinced it will require new resources. The battle against AIDS will be a costly one both in terms of money and energy. Considerable sums of money must be allocated by all levels of government to deal effectively with AIDS. It must be "new money" and not funds taken from other already underfunded health sectors and social services. To give into the temptation to drain other areas of equal need is both unethical and socially divisive.

This collective effort must take place at the community level, guided by effective strategies and appropriate methods of intervention and care. We are convinced that our society possesses the potential, but lacks the financial means at present. The financial commitment required is substantial, but is essential for Canadians both now and in the future.

Recognized Needs and Model of Intervention

Our survey of Canadians who care for AIDS patients demonstrated the needs of persons with AIDS and their families and friends are clearly understood and identifiable. Where a support system does not exist, a network of physical, psychological and social support must be established without delay; where such systems are already developed, they must be given generous support. Where there is even one case of AIDS, palliative care is necessary. The time to act is now -- delay is only contributing to the suffering of many Canadians.

In this report, we show that a realistic and appropriate model of AIDS care can be developed. What we propose includes only the components and the guidelines, as each community must structure and tailor its program to suit its own specific needs.

Public Health

Canada, as never before, is confronted with a great and undeniable public health problem, and its job now is to promote and protect the physical, mental and social well-being of its people. We must exercise this responsibility by first and foremost meeting the needs of the people already affected by the virus and the disease. We must also prevent the spread of the virus by establishing programs that have been recognized as effective and appropriate to the present situation. It is a responsibility governments can no longer ignore.

Here and Now

Here we are in 1989 with over two thousand cases of AIDS in our country and with tens of thousands more Canadians infected with the virus. The virus already has an eight-year head start, and there is no time for further deliberation on the nature of the issues. Concerted action by all levels of government must take place NOW.

If we delay further for fear of making a mistake, we run the risk of committing a monumental error -- the error of having done too little, too late.

From the Members of the Expert Working Group

Lesley Degner
Michael Downing
Margaret Fietz
Irene Goldstone
Elma Heidemann
Johanne Mousseau
Jean Robert

Conclusions and Recommendations

Our area of study has been palliative care for persons with AIDS; however, in studying palliative care, we had to look at total care. Our recommendations reflect not only palliative care specifically, but also more general concerns for care.

(1) In a free and democratic society such as ours, the dignity of the individual has always been paramount, and perhaps nowhere is this basic tenet expressed so clearly as in our attitudes toward the sick and dying. The concept of quality of life and its companion, the quality of death, are important expressions of this respect for the individual -- concepts that are an integral part of the philosophy of palliative care. The growing numbers of Canadians with AIDS require and deserve a meaningful life and a dignified death.

We RECOMMEND that governments at all levels -- federal, provincial and municipal -- actively promote the development of palliative care services in their jurisdictions so all persons with AIDS and their families and friends have access to palliative care services from the time of diagnosis through death and bereavement.

(2) Our survey and site visits demonstrated that, while the needs of persons with AIDS and their families and friends are well-known and clearly definable, many of the services required are either inadequate or non-existent. This situation is unacceptable, as the needs of persons with AIDS and their loved ones are both immediate and growing. New and additional funds are necessary now so the development of palliative AIDS care services does not come at the expense of other equally deserving services. Diversion of already inadequate funding would be both unethical and socially divisive.

We RECOMMEND that provincial governments make new and additional funds available immediately to health care provider groups and other appropriate organizations to expand or develop palliative care services designed to meet the needs of persons with AIDS and their families.

(3) Our established system of health care delivery is challenged by AIDS in ways it has never been challenged before. AIDS is a disease with far-reaching medical, social and societal implications. Care of AIDS patients requires the multidisciplinary team delivery of health and social services, in conjunction with community and volunteer support, to allow for care to be given in both home and institutional settings. In addition, as our survey findings show, the psychosocial needs of persons with AIDS and their loved ones should be given high priority. We believe that in this service delivery challenge lies the potential for a new and positive change in the cooperative delivery of health and social services in Canada.

We RECOMMEND that health care provider groups, with the financial and consultative support of provincial governments, develop an integrated and comprehensive network of palliative care for persons with AIDS and their families and friends.

(4) AIDS is a worldwide problem; yet, like other global issues, the solutions reside at the community or regional level where services can be most effectively and efficiently developed, administered, delivered and evaluated. Some communities are already reorganizing and mobilizing their care delivery systems; others will need financial and program support to begin this task.

We RECOMMEND that, with the financial support of federal, provincial and municipal governments, the planning, coordination and delivery of AIDS care be initiated in each community or region of Canada.

(5) No one should underestimate the difficulty of creating a multidisciplinary approach to care. It is a philosophy that is much espoused, yet rarely actualized. Barriers must be removed among professional and community groups so information and skills are both publicized and shared. It will require skill, commitment and money to create the links necessary to bring together the many health care, social service, community and volunteer components into a cohesive and integrated system of care. We believe this objective can be best promoted through the creation of prototypes to test different arrangements of services and to discover what structures work best in different communities and regions across the country.

We RECOMMEND that, while palliative care initiatives are expanding across Canada, special pilot projects must be undertaken to demonstrate and evaluate the efficacy and effectiveness of the proposed model included in this report and other alternative models of health care delivery for persons with AIDS and their families and friends. Such projects may include an economic evaluation of these models.

(6) Little or no information is available on the different models of AIDS care. We believe that health care dollars cannot be properly allocated without factual information about care in different settings and by different providers. The increasing number of AIDS cases only adds more urgency to the need for a sound database. Further, we believe the survey undertaken for this report should be repeated two years from now to determine the effect that increasing experience has had on the perceptions of Canadians involved in the care of persons with AIDS.

We RECOMMEND the research-funding bodies in Canada make a commitment to the study of AIDS care by becoming active solicitors and supporters of research to improve the care of persons with AIDS.

(7) AIDS challenges not only the organization of our health care and social service systems, but also those who work within it. Along with new models of health care delivery, new attitudes and perspectives must be developed by those who work with persons with AIDS and their families and friends. As well, health care and social service professionals and volunteers will need to increase their knowledge and skills in both acute and palliative AIDS care. Education at all levels will be necessary if compassionate, effective multidisciplinary care is to become a reality. Workshops on palliative care of persons with AIDS, monographs on palliative AIDS care and national conferences to bring about the necessary clinical and curricula changes are a few of the steps that should be taken now.

We RECOMMEND that Health and Welfare Canada provide funding and consultative support for the education of all caregivers of persons with AIDS and their families.

(8) We believe that a national policy direction is essential to the development of a universally equitable and accessible system of care for all persons with AIDS and their loved ones.

We RECOMMEND that a national policy for the care of persons with AIDS and their families be developed by Health and Welfare Canada to ensure a comprehensive approach to AIDS care consistent with the Canadian principle of universal access to health care.

(9) Finally, and most importantly, it should be recognized that AIDS and Human Immunodeficiency Virus infections pose a serious threat to Canadian society. The Working Group believes that with the completion of this report, our work has only just begun. Our personal commitment has in fact increased. Canadians can no longer deliberate. We must act now.

We RECOMMEND that all levels of government accept responsibility for taking immediate action on the foregoing recommendations.

Chapter One

Introduction

1.1 Terms of Reference

In October 1985, the Parliamentary Standing Committee on National Health and Welfare undertook a study of the major concerns and problems surrounding the issue of AIDS in Canada. Based on testimony from leading experts in the field of AIDS care, the Committee published the *Report on AIDS in Canada* in May 1986. This report contained 23 recommendations for national action on AIDS, of which Recommendations Number 14 and 15 state:

The Standing Committee recommends that, in conjunction with AIDS patients, a group of experts involving the Palliative Care Foundation, economists, hospice operators and public health officials develop a model for integrated palliative care for AIDS patients.

The Standing Committee recommends that a cost-effectiveness analysis be undertaken to examine the model for integrated palliative care as opposed to the present methods of caring for AIDS patients. It is important that the concerns and requirements of AIDS patients and their family and friends be considered in the model.

To develop a "model for integrated palliative care," an Expert Working Group was formed and held its first meeting on November 11, 1986. The Working Group's first task was to define its terms of reference. The Oxford Dictionary defines a *model* as "a particular design or style of structure regarded as excellent of its kind and proposed for imitation" while the word *integrate* is defined as "to combine parts into a whole."

Palliative care is defined as the active, compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional aims of cure and prolongation of life, and when the emphasis of care is on comfort and quality of life until death. Palliative care is delivered by a multidisciplinary team able to meet the physical, psychosocial and spiritual needs of dying persons and their loved ones. In palliative care, both the dying person and the loved ones are the unit of care, and care of the patient's family and friends extends after death has occurred.

Thus, the Working Group's aim was to find a structure for caring for terminally ill AIDS patients and their families that was composed of numerous parts and, when considered as a whole, could be proposed to others for imitation. Our task was to identify all the components of palliative care for persons with AIDS and their families and friends, look at how to put those components together and then describe for others how the resulting structure could be put into place.

The Working Group set out its objectives as follows:

- to explore and assess existing arrangements of care for persons with AIDS and their families and friends
- to explore and assess selected Canadian and United States experiences in palliative care for persons with AIDS and their loved ones
- to consult with community AIDS groups regarding perceived needs for palliative care
- to make recommendations about potential models of integrated palliative care on the basis of findings from the above

1.2 Membership of the Expert Working Group

The Federal Centre for AIDS, in collaboration with the Health Services and Promotion Branch of Health and Welfare Canada, identified individuals from various

disciplines across the country who were involved with providing or planning palliative care for persons with AIDS. The Working Group was established in October 1986, and its membership included:

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Health Services and Promotion Branch
Health and Welfare Canada
Ottawa, Ontario

Greg Smith, B.A., D.P.A.
Executive Director
Federal Centre for AIDS
Health and Welfare Canada
Ottawa, Ontario

1.3 Meetings

The Working Group met a total of six times between November 1986 and December 1987, in addition to numerous meetings held by subgroups.

1.4 Acknowledgements

The Working Group received a great deal of assistance from many sources during the course of its work and wishes to thank all who participated in any way.

Chapter Two

The Working Group's Investigation

To carry out our task, the Working Group looked at two specific areas. First, we examined the medical and psychosocial needs of persons with AIDS and their families and friends. Our aim was to be as specific as possible about the nature and relative importance of these needs. Second, we looked at how those needs translated into services.

Our investigation involved a questionnaire survey of Canadian institutions, community services and persons with AIDS. This information was then supplemented by the findings of site visits to specific AIDS care facilities and programs in Montréal, New York City and San Francisco. Site visits were not considered necessary to other cities in Canada with large numbers of persons with AIDS, such as Toronto and Vancouver, since the Working Group was able to draw on the expertise of its members for the necessary data.

2.1 A Survey of Canadians Who Care for Persons with AIDS and Their Loved Ones

A questionnaire was developed by the Working Group to elicit the opinions of Canadians who care for persons with AIDS. The questionnaire had two parts: the first requested demographic information about the nature of the respondent's program, while the second asked respondents to rate the importance of eight issues of care considered by the Working Group to be critical in the care of AIDS patients and their loved ones. These issues were:

1. Symptom Management
2. Psychological Support
3. Interpersonal Support
4. Independent Living
5. Legal/Financial Support
6. Lifestyle/Cultural/Ethnic/Religious Considerations
7. Service Delivery Needs
8. Bereavement Support

We identified four categories of respondents for the questionnaire:

1. Hospitals
2. Palliative Care Programs
3. Public Health/Visiting Nurse Services
4. Community-Based AIDS Groups

Questionnaires were sent to 160 agencies that indicated a willingness to participate in the study. Respondents were selected from across Canada to reflect national experience. Respondents were also selected to ensure that the survey would reflect varying amounts of experience in caring for persons with AIDS and their loved ones.

The questionnaire was field tested and the survey conducted by the Manitoba Nursing Research Institute under the direction of Dr. Lesley Degner.

A total of 84 questionnaires were returned for a response rate of 52.5 percent. Respondents were drawn from every region of the country and included 27 hospitals, 28 palliative care programs, 15 home care/visiting nurse services and 13 community-based AIDS groups. Most programs (58%) had experienced three or fewer deaths of persons with AIDS. Very few of these deaths (13%) occurred in the home environment.

The respondents viewed the provision of psychological support, including help in managing feelings of loss, anger and fear, as the most important issue in palliative care for persons with AIDS. The next most important issue identified by these caregivers was the need for persons with AIDS to receive interpersonal support from parents and siblings, friends, lovers and caregivers. Service delivery considerations, including issues surrounding infection control, were ranked as third in

overall importance. Symptom management was ranked fourth in importance, with fatigue, oral care, dyspnea and diarrhea identified as the major factors in providing physical care.

While palliative care programs have arisen primarily in response to a need for improved symptom management among people dying as a result of cancer, the dominant issue in the care of persons with AIDS is clearly **not** one of symptom management. The overwhelming nature of this disease produces profound psychological and interpersonal problems for those affected. Caregivers in a variety of agencies and the friends and family members of people with AIDS are struggling to provide what support they can in the face of limited health care and personal resources. The primacy of psychological and interpersonal support issues in the care of people with AIDS suggests that any model of palliative care must include funding for personnel resources dedicated to addressing these needs.

The survey concluded that the central factor influencing perceptions of the respondents was the number of AIDS-related deaths they had experienced. When first confronted with the challenge of caring for people with AIDS, health personnel and community members had to master their own anxieties and learn about the disease. As this mastery was achieved, concerns about personal vulnerability decreased and a sense of commitment to providing the required services developed. However, as the number of deaths increased, the concerns resurfaced in a different form. Who is going to provide all the services that will be required in the future? Only those who are already committed? Survey respondents wanted to share the responsibility for care, but were afraid that others might not become committed enough to do so.

Findings of the survey also suggested directions for future research. Studies are needed to determine the most effective strategies to provide psychological support to persons with AIDS and their families and to reduce the mental health risk to survivors. Research is also needed to compare the effect of community-based and hospital-based models of care on a variety of variables. Finally, it would be useful to repeat this survey in two years to determine the effect that increasing experience has on the perceptions of what are the most important needs of persons with AIDS.

A detailed report on the survey findings is in Appendix II.

2.2 Site Visits

Three major cities experienced with delivering care to persons with AIDS and their loved ones were selected for site visits -- Montréal, New York City and San Francisco.

2.2.1 Montréal

This pilot site visit was conducted in January 1987 and served as a basis from which protocols were developed for the site visits in the United States during March 1987.

In Montréal, care for persons with AIDS is primarily a hospital-based system supplemented by a newly emerging community service network. Persons with AIDS had access to services through provincial health insurance; however, outpatient drug and nutritional supplement costs were not funded by the province of Quebec. Therefore, some Montréal hospitals were subsidizing these costs. This burden creates an increased strain on hospital budgets which can only be eased by the availability of additional resources.

To meet the psychosocial needs of persons with AIDS and their families, social workers in Montréal are having to "forge new ground" to be both educators and service innovators. All members of the care team were confronted with issues from this new patient group, issues which are not usually within their service expertise.

In Montréal, a major palliative care service was concerned its limited resources would be overwhelmed if it took a major role in caring for AIDS patients.

2.2.2 New York City

In New York City, the care of persons with AIDS and their families is perceived to be primarily a hospital responsibility, that is, the hospitals are seen as the organizers of care, whether that care is delivered in a hospital bed or in the community.

New York City accounts for almost one third of all AIDS cases in the United States. Despite the highest incidence of AIDS in North America and many years of experience with the disease, New York City is only just beginning to develop a regional system of care. Due to the high incidence of AIDS among women and children in New York City, a special effort has been made to involve extended family members in the delivery of care to these groups and, as much as possible, care is given in the home setting. Home care is not always practical, however, because New York City's general housing crisis and the socioeconomic status of many Blacks and Hispanics often means that the patient's home is not considered safe or adequate for home care. Also, as hospitals are the organizers of care, the provision of home care has placed an additional burden on already overtaxed hospital personnel who must then provide care in both settings.

Entry into the health care system is problematic in New York City, since the system does not provide for universal access. Financial costs of care are very high, both for the individual and the institution providing the care.

In New York City, attempts are being made to ensure that continuity of care is provided to persons with AIDS whether they are in the hospital or using available community services. Relatively new types of health care providers, such as nurse practitioners, physician assistants and home attendants, are being employed to achieve improved continuity of care. The Gay Men's Health Crisis Centre Inc. has developed an effective network of services and educational programs. As well, the Crisis Centre is reaching out to persons with AIDS from other lifestyle, cultural and socioeconomic groups.

In the sites visited, social work departments were attempting valiantly to meet the overwhelming needs of this new patient group and their families, but their resources were stretched very thinly. Also, the need for inservice training and support groups for hospital staff was emphasized repeatedly.

2.2.3 San Francisco

San Francisco's care system for persons with AIDS and their families was the most highly developed system encountered by the Working Group. Among the reasons were the sheer size of its AIDS population; the large and powerful lobby group within the city's gay community; the early support given by the political hierarchy of the city and the state; and an early recognition among the various provider groups that there would be little chance of preventing a full-scale crisis unless they worked together.

The network of services in San Francisco includes education, community emergency care, both inpatient and outpatient hospital care, hospice (palliative) care, and professional and volunteer community-based services. It should be noted that the services of volunteer groups are critical to the network of care in San Francisco.

Care in the home is a central feature of San Francisco's network of services, both for quality of care reasons and to minimize the costs of care. It is delivered by a variety of professional and volunteer groups.

The primary entry point into the network of services is through the outpatient clinics of the San Francisco

General Hospital (a city and county hospital), although a person can gain access to the entire care system from any level and through any provider. Outpatient clinics serve as a coordination centre where representatives of most care provider groups are either physically located or available at scheduled times during clinic hours.

A 20-bed inpatient unit is also located at the San Francisco General Hospital. Demands on this unit are increasing rapidly, and thought is now being given to establishing a greater number of long-term care beds elsewhere in the city to support the inpatient unit. Additional beds would not only help to ease the burden on the unit, but also would permit care to be delivered in more appropriate locations for some patients. It is also anticipated the present private rooms on the unit will be converted to double rooms to accommodate increased numbers of patients.

Additional innovative community-based services exist in the area. The AIDS Foundation of San Francisco provides emergency housing and a food bank for persons with AIDS. As well, it operates -- entirely with volunteer manpower -- a hotline for AIDS for the state of California. The Shanti Project is an impressive volunteer service which provides practical assistance and psychosocial support for those able to remain at home. Home care services are also available through the Visiting Nurses Association of the Hospice of San Francisco. A newly formed hospice program has a small number of beds as well as home support services.

The possibility of continuing care throughout the illness in appropriate locations and delivered by appropriate persons appeared to be good in San Francisco. There was an excellent range of services and goods, if somewhat informal, mechanisms for cooperation among the provider groups to service individual patients and their loved ones.

The establishment of this impressive network of services for persons with AIDS and their families and friends did have, we were told, negative repercussions for a time on care of persons suffering from other terminal diseases, especially cancer. While this situation appears to have been rectified, it did create serious problems both in hospital and community-based services.

A more detailed report on the site visits by the Working Group is in Appendix III.

2.3 Summary of Survey and Site Visits

Survey results and our site visits have been organized into five sections which we believe are key areas of consideration to develop a system of palliative care for persons with AIDS and their families and friends.

2.3.1 Care for Persons with AIDS and Their Families and Friends

Our research led us to conclude that a wide range of services, provided by a variety of health care professionals and others, were necessary for quality care of persons with AIDS and their loved ones. It also led us to conclude that such care was best delivered by a well-coordinated team of individuals comprising both professionals and volunteers.

The survey helped us to describe the variety of services required. Our research also helped us to understand the need for these services may be different during the various stages of illness, from diagnosis to death. It was quite apparent from both our survey and site visits that psychological and social support are of paramount importance throughout the illness, but most particularly during the terminal stage when death is near.

Both the site visits and the survey clearly indicated that mental deterioration is an important consequence of AIDS. The latest statistics indicate that some form of mental deterioration, ranging from mild and stable to severe and rapidly changing, is present in approximately

60 percent or more of persons with AIDS. Mental deterioration is a major problem during the terminal stage of the illness and creates specific care needs that may even result in the need for special facilities. Because mental deterioration may occur at any point in the disease, there is a need for persons with AIDS to settle their affairs early while able to do so. Such things as making a will must be done at an appropriate time, and assistance may be a necessary service.

2.3.2 Care Delivery

Our research showed the person with AIDS, the caregivers and the family should jointly share the decision as to the type and location of care. We also learned that the availability of different care options is important. For example, it is highly desirable for persons with AIDS who wish to remain in their homes to do so. During the site visits, we discovered many innovative approaches to providing care in the home, and it is clear that quality care for persons with AIDS can be provided in the home, if there is the will and determination and the resources.

The importance of care in the home does not, we learned, diminish the importance of high quality institutional care when required. Repeatedly, we heard of the need to plan institutional services carefully, not after crisis has struck. Repeatedly, we heard of the need to train staff properly and to provide patients with both caregivers and environments sensitive to the needs of persons with AIDS and their loved ones.

What is needed is a carefully integrated network of care composed of both community-based and institutional services. If persons with AIDS and their loved ones are to receive high quality care, then they must be able to receive what they require, when they require it, in the most appropriate location. Needless to say, such a network does not magically fall into place. Rather, it takes considerable thought, planning, cooperation and hard work to achieve.

Persons with AIDS certainly require medical services, but our research indicates that there is also an equal, and in some instances, a greater need for what are usually thought of as social services. We learned that it was necessary to achieve a balance between the medical and social dimensions of care. We were told many times that this need is frequently an issue when funding allocations are made, that is, social dimensions are generally funded poorly. Failure to provide adequate social service support affects not only the person with AIDS, but the caregivers as well. Where social services are lacking, medical and nursing staff often attempt to provide social service support in addition to their other caregiving responsibilities, resulting in staff "burn-out."

In addition to loved ones, caregivers of persons with AIDS may also include other professionals and volunteers. Many examples of strong, well-organized community volunteer groups exist, and their contribution to the delivery of care is well documented. Both professionals and volunteers have appropriate roles to play, and a strong care team can emerge if their roles are clearly identified and if they work together.

The feasibility of mixing AIDS patients within an institutional setting is another issue which emerged during the site visits. There is no clear consensus on the issue of mixing AIDS patients either within the AIDS patient group itself or with other patients. What appears certain is that the volume of patients will most certainly influence any decision with regard to aggregating or integrating AIDS patients within the general hospital population to minimize the stigma presently associated with this disease.

A final care delivery issue which emerged from our site visits was the repercussions of AIDS on care available to persons suffering from other terminal diseases. We were given examples in the United States of how care for terminal cancer patients suffered through diversion of resources when the number of terminal AIDS patients reached significantly large numbers.

2.3.3 Education

For the purposes of this report, three specific education issues for caregivers are relevant. The first is the education of caregivers about the course of the disease as well as the types of care required at various stages in the illness. The second issue is educating caregivers as to how they can protect themselves from getting AIDS -- specifically teaching infection-control techniques which are both adequate for protection and as humane as possible for the person with AIDS. Both these education needs involve the acquisition of technical skills and the recognition of the natural fears which arise for caregivers when dealing with AIDS. Both are necessary to ensure quality care throughout an individual's entire illness, but are of utmost importance in the terminal stage when contact with the person with AIDS is at a maximum and when the need for care is most demanding.

The third education issue for caregivers -- and the most difficult to achieve -- involves understanding the lifestyle and values of persons with AIDS and their loved ones. Without such an insight, the care provided may be technically superb but incomplete. Such a lack of understanding may also lead to forms of discrimination which, in turn, results in physical and emotional hardship for those with AIDS and their families and friends.

2.3.4 Support for the Caregivers

Our site visits confirmed that the psychosocial needs of caregivers must also be considered. Support programs for both professional and volunteer caregivers are needed which allow for ventilation of the complex range of feelings surrounding the demanding task of caring for young, terminally ill persons with AIDS.

2.3.5 Policy

Repeatedly, during our site visits, we heard of the need for policies, especially government policy, which would provide a basis on which care for persons with AIDS and their loved ones could be developed.

In practical terms, we learned that effective networks of care for persons with AIDS and their families emerged when governments at various levels first made a commitment in policy to create these networks and then backed up these commitments with funding allocations. We also saw the reverse, where lack of commitment impeded the establishment of adequate networks of care. We learned as well that policy regarding research, education, prevention and testing appeared to be of top priority, with policy for the care of persons with AIDS and their loved ones, especially in the terminal stage of illness, falling behind. We must question whether or not this minimal emphasis on care is appropriate.

2.3.6 Economics

The economic issues associated with AIDS are many, varied and largely unexplored. For our purposes, the economic issues were divided into two broad categories: those concerned with the individual with AIDS, and those concerned with the costs to the health care and social service systems.

For the person with AIDS, there is generally a sharp decline in economic status, since the illness frequently leads to loss of employment and income. In turn, unemployment may result in draining all savings and assets. The person with AIDS may be forced to depend on loved ones or the welfare system for support. A productive, contributing member of society may be reduced to a completely dependent existence.

The effect on the individual is, of course, devastating; however, there is also a significant cost to society. The

nature and magnitude of this cost, however, has yet to be examined.

The second economic issue is the cost of caring for persons with AIDS within the health care system. Our health care system is already overextended, and AIDS will add a considerable strain on the system. The impact of AIDS will be felt particularly by the currently underdeveloped and underfunded palliative care system.

The high cost of drugs for persons with AIDS has emerged as an issue, but there are many more serious cost issues yet to be explored. For example, we have no reliable cost data that tell us about the overall costs of caring for a person with AIDS during the entire course of the illness. Current United States estimates indicate that the cost of caring for a person with AIDS during an entire illness is between $40,000 and $50,000. While these figures are often quoted, they are difficult to substantiate. Similarly, there are little cost data regarding the difference in the cost of caring for a person at home versus an institution. Nor do we know just how much care can be delivered at home and at what cost.

We know from our survey that expensive institutional care is now being used because there is no alternative service, not because the person requires or prefers institutional care. We also know from our survey and site visits that expensive hospital care is now being used when less intensive and less expensive institutional care, such as nursing home care, would be more appropriate.

Of particular relevance to the terminal stage of illness is the fact that many persons with AIDS would prefer to die at home, but the necessary services are not available. Needless to say, these dying persons also occupy expensive hospital beds because no other alternatives are available.

We concluded from our site visits and survey that the study of many of these cost issues must begin now so that, as the number of AIDS cases increases, the allocation of our scarce health care resources will be efficient, effective and will result in quality care to persons with AIDS and their loved ones.

Chapter Three

A Model of Integrated Palliative AIDS Care

Based on the findings of the survey and site visits, the Working Group believes that *there is a clearly definable set of services required by AIDS patients and their loved ones, and that these services must be developed and delivered within an organizational structure which integrates the community and the health care systems into a fully coordinated network of care delivery*. As will be seen, there are many ways in which these services may be provided, and each community must determine the structure that most effectively and efficiently delivers those services.

To assist communities in developing their own AIDS care program, we constructed a two-part model. The first part, ***a Model of Palliative AIDS Care*** (Section 3.2), outlines the needs of persons with AIDS and their loved ones and describes the interrelationship among the acute care system, the palliative care system and the various community agencies. The second part, the ***Model of Care Delivery*** (Section 3.3), suggests a community structure through which these services can be effectively delivered.

Before exploring the actual model, it is important to clearly understand the principles upon which palliative care has developed in Canada. This knowledge is necessary to ensure that the system ultimately developed by a community will incorporate these principles in its foundation.

3.1 Principles of Palliative Care

In Canada over the last 10 to 15 years, there has been significant growth in the awareness of and the response to the needs of terminally ill patients and their families. Hospice and palliative programs are present in over 350 communities across Canada; unfortunately, these programs serve only 10 to 15 percent of the terminally ill patients. Throughout this rapid growth, palliative programs have maintained common threads of philosophy and function. These threads, although stated and expressed in many different ways, underscore the values which our society places upon human life and death, and form the basis to implement care for the dying.

There are two general ways of outlining the principles of palliative care: first, as **philosophy** and second, as **program components** necessary to provide care.

3.1.1 Philosophy

Although there is no set or specific philosophy of palliative care, there are several general statements common to palliative care programs in Canada. Some of these statements can be used to form the basis of program development. A few examples are listed here:

1. Death is seen as a natural part of life and is acknowledged rather than seen as a failure which must always be fought against to the very end.

- "Life is not the ultimate good, nor death the ultimate bad."[3]

- "It is still difficult for most medical and nursing personnel to see palliative care as a positive action full of right choices and comfort rather than as a failure of active care."[4]

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[3]Paraphrased from the Law Reform Commission of Canada Working Paper 28, *Euthanasia, Aiding Suicide, and Cessation of Treatment*, 1982, 4.

[4]B.C. Hospice/Palliative Care Association Brief, *Palliative Care in British Columbia*, September 1986, 4.

2. The unit of care is both the patient and the loved ones; although death is personal, its meaning and impact are wider. The family must be integrally included in planning and care.

3. Palliative care upholds the basic dignity and worth of human kind whether living or dying. People who are dying are still living and have the right to be in control of their lives, including refusal of treatment or the continuation of it.

4. The primary intent of care is palliative or "comfort-oriented." The relief of distressing symptoms, especially physical, is paramount.

5. The needs of the terminally ill are often diverse and best met by a variety of skills from the professional disciplines, volunteers and the family.

6. Coordination and consistency of care is essential among disciplines and between facilities.

7. Creation of "home" -- wherever that may be -- is necessary for proper care.

8. Grief support for the family following death is an essential part of care for the dying.

9. Support for caregivers is essential to their ability to continue working effectively in an area of pain, death and loss.

3.1.2 Program Components of Palliative Care

As palliative care has emerged to address the philosophy described above, programs have formed a variety of services or program components. The following points are the recognized program components, developed by the British Columbia Hospice/Palliative Care Association,[5] and are examples common to most other areas in Canada.

1. Symptom Control Component

Dying patients face a myriad of symptoms of which pain is very common, but which also include nausea, shortness of breath, profound weakness, incontinence, confusion and others. Control of these symptoms is essential to restore both the patient's comfort and dignity. A palliative care team of professional health care providers, trained in palliative care, can significantly control and often prevent crises induced by various symptoms. This component forms the foundation or basis of palliative care.

2. Administrative Component

This component recognizes that palliative care is not just a philosophy, but a specific program of care services. The needs are too great and the boundaries tood iverse for palliative care to be effective simply by everyone having a "good attitude" toward palliation.

3. Home Component

To die at home is comforting to most people, providing sufficient help is present. Hospice programs support, wherever possible, death at home through a variety of services. These services are often contracted with or even based in present home health services. Further, death may not be possible at home, but "home" can be created in facilities of care. This component provides types of supports which recognize and enhance home, wherever that may be.

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[5]Taken from the B.C. Hospice/Palliative Care Association By-Laws, Section 24.4. of care services.

4. Hospital Component

Where death at home is not practical or desirable, programs may develop special palliative supports for those in hospital settings. The program may include a designated ward or palliative care unit, or a palliative consultation team. These facilities include acute care and long-term care hospitals.

5. Volunteer Component

Death is a part of all our lives. It is not just a "professional" concern. The volunteer brings a special blend of normality and daily reality into the care of the dying which is just as significant as the "hours of volunteer service" contributed. Programs which use volunteers effectively provide a volunteer service of recruitment, training, coordination and support to volunteers through qualified volunteer coordinators.

6. Spiritual Component

Questions, anticipations, fears and hopes are some of the inner dimensions for persons facing death. This component acknowledges the wide diversity of beliefs, customs and feelings surrounding death and offers professional and volunteer support.

7. Bereavement Component

The loved ones live through the death of the person and beyond. They enter a new world, one in which that person is now absent. In the face of their grief and fears, they need to re-order, rebuild and renew their lives. For some with many supportive friends, this process may occur easily; but for others, it is a very difficult and frightening period. Following death, professional and volunteer support is provided through a program of grief support to families and friends to facilitate "good" grief, and healthy re-connections.

8. Education Component

Since death is often avoided by both professionals and society, education is very important. Significant advances in pain control and management of other serious symptoms are only part of the new areas for education. Understanding grief reactions and appropriate supportive measures are widely requested. This component crosses many public and health boundaries in providing better understanding of the process of dying, and needs of patients and loved ones.

9. Evaluation/Research Component

As palliative care programs emerge, there arise questions about quality, effectiveness, further new developments, and so on. This component is essential to all health care fields and certainly to the new and evolving area of palliative care.

3.2 A Model of Palliative AIDS Care

The Working Group developed a model of care for AIDS based on **four factors:**

- the **stage** of the disease Section 3.2.1
- the **intent** or aim of treatment Section 3.2.2
- the **needs** of AIDS patients and their loved ones Section 3.2.3
- the **methods** of delivery of a care model Section 3.3

These four areas are explored in Subsections 3.2.1 to 3.2.3 and Section 3.3. Further discussion in Sections 3.2.4 and 3.2.5 concerns the "who" and "where" of care.

3.2.1 Stages of Acquired Immunodeficiency Syndrome

This syndrome is expressed in a variety of ways or stages over time. Appendix IV entitled "AIDS Disease Trajectory," contains a more detailed discussion of the manifestations of AIDS and the kinds of problems which the patient may encounter.

To develop a model of care, we chose a simple four-stage process. The stages described below are not always clear-cut, nor are they always the same for each AIDS patient. They are, however, significant in relation to what services are needed and at what point they should be provided.

(1) EARLY Stage

This stage is characterized by a recent diagnosis of AIDS, good response tc active therapy, recovery of function and weight, and the ability to resume normal activities and work.

(2) PROGRESSIVE Stage

This stage is characterized by the episodic occurrence of opportunistic infections and a shortening interval between each infection. Active therapy will likely continue, and there may be some improvement in the patient's health, but increasing incidents of treatment side effects may also take place. Gradual and progressive weight loss occurs, along with increasing and persistent fatigue. Some behavioural changes may occur due to neurological or mental impairment. Partial activity is the norm, and work may be possible if it is not physically demanding.

(3) ADVANCED Stage

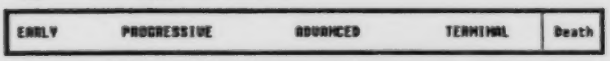
In this stage, fatigue and debility seriously affect daily function. Some neurological manifestations such as dementia or blindness may occur. Infections are either constant or worsening, and active treatment has limited effect. By now, if not before, aggressive treatment should be stopped, and carefully shifted to palliation.

(4) TERMINAL Stage

This stage is blurred with the Advanced Stage. Death may or may not be imminent. Care is entirely comfort-oriented through death. Supportive care is continued to loved ones through both death and the subsequent bereavement period.

These four stages of AIDS from diagnosis to death are illustrated in Figure 2. This diagram is used in a "building block" fashion along with other diagrams discussed in the next few pages to build the Model of Care.

Figure 2: Stages of Disease

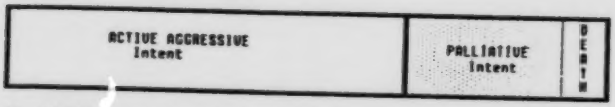


3.2.2 Intent of Treatment

Medicine has historically divided care into two categories: curative and palliative. The first and highest aim of treatment is to cure a disease. When cure is not possible, medicine aims to alleviate or palliate the disease through control and relief. Many diseases, such as arthritis or hypertension, may not be cured, but can effectively be controlled. When cure or control is not possible, palliative measures may still provide relief and comfort from the effects of the disease.

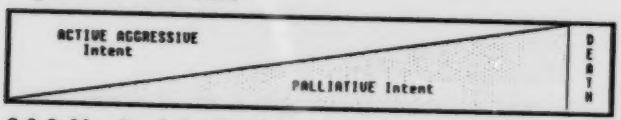
Palliative care, as a specific program, evolved mainly through the management of patients with terminal cancer. With cancer care, there is often an early period of active and aggressive treatment followed by a reasonably clear transition to pure palliative comfort care. (See Figure 3.)

Figure 3: Cancer Care



In AIDS care, there is not necessarily such a clear transition. Active, aggressive treatment is often continued until close to death. However, as the present outcome is always fatal and the lifespan much shorter than cancer care in general, preparation for death and integration of palliative care services should begin at diagnosis. Therefore, the division line between aggressive and palliative care is somewhat blurred at all points along the AIDS disease trajectory. This profile is in contrast to the usual form of cancer treatment as seen in comparing Figures 3 and 4. *For AIDS care, the Working Group feels palliative aims must begin at diagnosis and be integrated with aggressive aims to provide optimal care.*

Figure 4: AIDS Care



3.2.3 Needs of the Palliative Patient with AIDS

Based on survey results and the Working Group's experience, we determined that the needs of AIDS patients fall into **eight categories**. To develop the Model of Care, each of these areas must be addressed throughout the changing stages of the disease. These categories are restated below in the **order of priority** as found in the survey:

1. Psychological Support

The individual facing death experiences a complex of psychological reactions such as anger, depression, hopelessness or unrealistic hope, fear and feelings of worthlessness. They are natural reactions which require help and support so the integrity of the dying individual and the family can be maintained or even enhanced.

2. Interpersonal Relations

Adverse reactions from loved ones, the need for reconciliation, and fear and avoidance by people in general are only three examples of problems in interpersonal relations.

3. Service Delivery

Findings of the survey demonstrate that a wide spectrum of services must be available in a variety of locations. These services must be delivered by a multidisciplinary team with volunteer and family assistance and should include medical, nursing and social work services as well as technical support services for both acute and palliative care.

4. Symptom Control

Effective control of symptoms, such as pain, shortness of breath and incontinence, is essential to care, and these symptoms must be alleviated before other needs can be addressed.

5. Bereavement

Patients are often more concerned for their loved ones than for themselves. For healthy grieving to occur, appropriate support and follow-up is necessary for families and loved ones.

6. Independent Living

Allowing the individual and family control over decisions concerning care and the location of care is central to independent living.

As the disease progresses and mental debility increases, self-care becomes impossible, and additional support is

necessary if the individual is to retain some degree of independence. These supports may consist of both additional providers of care (family, friends, nurses, physicians and homemakers) and new options in the location of care (home, respite care, hospitals, long-term care facilities and foster care). See further discussion in Appendix V, "Location of AIDS Care."

Respect for the individual means that control must not be arbitrarily taken away from the patient. Joint patient/caregiver/family cooperation is essential if the patient's autonomy is to be maintained.

7. Legal and Financial Issues

The preparation of a living will and a last will and testament should be encouraged early in the disease. Many persons with AIDS are young and are without strong financial security. Loss of employment quickly leads to loss of self-sufficiency and poverty.

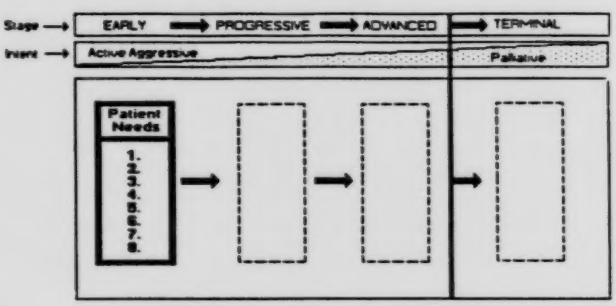
8. Lifestyle/Cultural/Ethnic/Religious Considerations

As AIDS spreads among all ages, lifestyles and cultures, there is a clear need to maintain sensitivity and understanding of each person's life views and values. Homophobia, racism and moralistic judgments are experienced and require active intervention. These reactions are not only centred in families, but are present in other areas such as the health care field, governments and churches.

It should be noted that the Working Group was intrigued by the priority of patient needs. *In cancer-related palliative care, the highest need has always been symptom control; here it is fourth. This contrast stands as a clear message for those developing palliative programs to recognize these differences and design their services accordingly.* At the same time, the placement of symptom control does not mean that medical/nursing expertise is unnecessary, but more that significant other supportive resources are needed to an equal if not greater degree along with these skills.

To build the model of AIDS care, these patient needs can now be applied to the stages of disease and the intent of care diagrams, and illustrated as in Figure 5. As can be seen, the needs of patients must be met at each stage as the disease progresses and as the intent shifts toward palliation.

Figure 5: Patient Needs and Stages



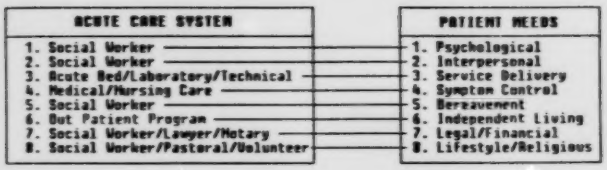
3.2.4 Who Is to Provide Palliative AIDS Care?

To meet the needs of the AIDS patient, many disciplines and systems involved in health care are necessary. At the present time, the **Acute Care System** is the main provider of AIDS care. Hospitals will remain primarily centres of active investigation and treatment. However, as few communities have other facilities or programs for AIDS care, acute care hospitals often become the only facility for both the early and terminal care of AIDS patients.

Figure 6 illustrates how a multidisciplinary hospital team might try to match patient needs with available services. Although, in this example, social work has primary responsibility for psychological needs, it should be emphasized that other team members must share this responsibility if patient needs are to be met, without

excessive strain being placed on only a few members of the team. Our site visit experience confirmed that where social work had sole responsibility for psychosocial needs, chronic exhaustion was evident in many workers. It is also worth noting that coordination of medical care and development of treatment protocols are critical to quality integrated care. Medical leadership in this area is important.

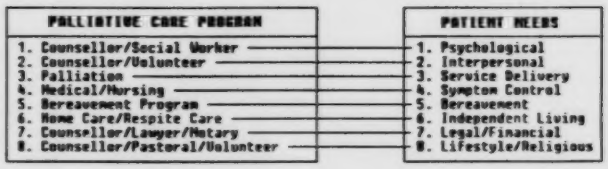
Figure 6: An Example of Care Delivery in Acute Care System



Acute care can be provided either in institutions or at home. Regardless of location, a multidisciplinary team approach is essential. There is a growing need to develop more community-based acute care services, such as outpatient and home care services. Furthermore, new ways of providing "acute care services" in the home setting must be encouraged. Some provinces have developed creative acute care services, such as the extramural hospital concept in New Brunswick. Home care service agencies are increasingly adding high tech procedures to their programs. Some of these concepts may be very appropriate to the AIDS care setting.

A second direction to explore in providing care for AIDS patients would logically be the **Hospice** or **Palliative Care Programs**. Where available, these programs vary widely in size, function and location. Those programs that are well developed have services which could effectively match the needs of AIDS patients, as shown in Figure 7.

Figure 7: An Example of Care Delivery in the Palliative Care System



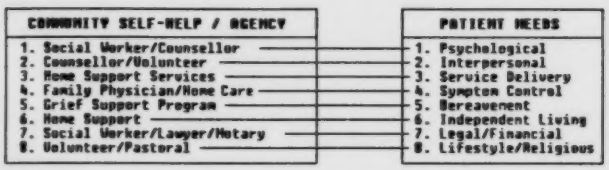
Some programs are **hospital-based** only and offer either specific palliative beds and units or a consulting team. Other palliative programs are **community-based**, offering home support services and consultation which are usually highly integrated with and even part of the existing home support network. A few provide both hospital and home services, allowing for further integration and coordination between services and facilities.

There are two main weaknesses of the palliative care system at present. The majority of these programs are very limited in size and often unable to meet the demands for cancer care, let alone other diseases such as AIDS. Significant funding support is required if they are to undertake AIDS care without reducing present care to terminal cancer patients. This situation is a real concern as seen in the site visit report from San Francisco. The second limitation is that palliative programs are specifically focused on advanced and terminal care, and do not usually become involved in the earlier aggressive treatment stages. Many programs need to revise their criteria and philosophy if ongoing and early stage care are to be integrated.

The third area to explore is the network of various **Community Services and Agencies**. It is obvious that the number, size and type of community services and agencies vary widely across Canada. Some are

government-funded programs such as public health or home care nursing services, and others are non-profit, private or self-help agencies, of which the various AIDS support groups stand out. An example of a match to meet the needs of AIDS patients is shown in Figure 8.

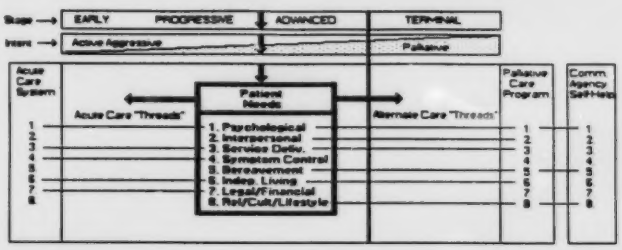
Figure 8: Example Using Community Services and Agencies



The Working Group concluded that it is difficult, if not impossible, to define one right way or Model of Care. It is conceivable that AIDS care could be provided by any one of the three systems just described; however, it is more desirable to combine the strengths of each. An integrated model acknowledges community differences, variations in provincial systems of health care and variations in patient requirements throughout the course of the disease. Further, this network of care recognizes the nature of AIDS as a societal disease. AIDS crosses all boundaries and disciplines in every community and to effectively "treat" the societal repercussions, the community at large must share the care.

The final "picture" of the integrated model can now be constructed. As Figure 9 illustrates, the needs of persons with AIDS and their loved ones can be met by different care systems interacting at different stages of the illness. While the active acute care system may predominate at one time and the palliative care system at another, the key characteristics of the care model must be flexibility and a willing collaboration among health professionals and volunteers to promote the independence and dignity of the individual. The model is further discussed in Appendix VI, "An Example of a Model of Care," where a case scenario demonstrates how to form a plan of care.

Figure 9: Model of Care



We believe that a multiplicity of services can be provided when care is shared among various systems and caregivers. Preference for one system may depend on the existing services within a particular community or on the stage of the illness. *Our research made it clear that no community can regard AIDS as solely a medical problem, requiring only a medical solution.* Persons with AIDS and their families and friends require a wide range of services which can be provided only when the responsibility for care is shared by both professional and volunteer sectors. Many times, roles will be blurred among the disciplines, as is commonly seen in traditional palliative care. Effective communication, coordination and clarification are key elements in such a system. Individuals involved in the delivery of care must include those from many health care disciplines and support services, such as:

- Medical -- Family Doctors and Specialists

- Nurses -- Registered Nurses, Nursing Assistants and Clinical Nurse Specialists
- Social Workers
- Clergy and/or Pastoral Care Workers
- Trained Counsellors, both professional and volunteer
- Lawyers and Notaries
- Homemakers
- Specially trained education staff
- Volunteers
- Family and friends

Many hands, many skills, for the many needs -- this Model of Care is the one every community must consider when developing its plan of care for persons with AIDS and their families. We turn our attention now to the structure necessary to implement such a plan.

3.2.5 Where Is Care to Be Provided?

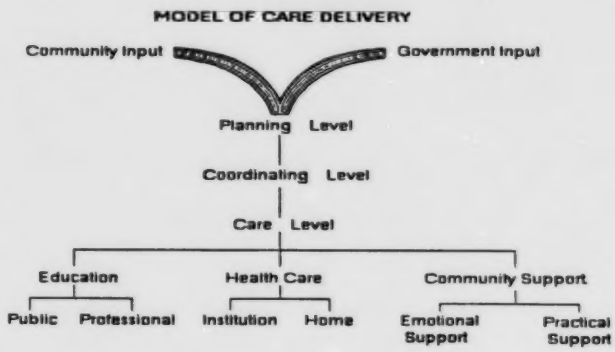
We believe palliative AIDS care can be provided in a variety of settings according to local community needs. These areas include the patient's home, acute care facilities, long-term care facilities, palliative facilities, etc. A more detailed discussion of the location of care and the interaction of community resources necessary for effective care is explored in Appendices V and VI.

3.3 A Model of Care Delivery for Integrated AIDS Care

The organizational structure to meet the needs of persons with AIDS and their loved ones is clearly a crucial element of an AIDS care system since plans and concepts are worthless without the mechanism to make them reality. The Model of Care Delivery in Figure 10 suggests such an organizational structure. It is important to note that this Model emphasizes both the use of existing delivery systems and community involvement in planning and implementing care.

As Figure 10 indicates, we believe that the impetus to develop a local AIDS care program must arise from the community itself with financial support and organizational assistance from municipal, provincial and federal levels of government.

Figure 10: Model of Care Delivery



Three levels or functions must be fully incorporated in any local care program -- the **Planning Level**, the **Coordinating Level** and the **Care Level**. In smaller communities, these levels may be carried out through two, or even one organizational body. In large communities or areas with a high incidence of AIDS, it may be appropriate to have all three as separate levels. *The important principle underlying this model is the integration and involvement of all segments of the community in assessing needs and taking the necessary action.*

3.3.1 Planning Level

3.3.1.1 Function

- maintain a broad, holistic perspective on AIDS care that anticipates future needs
- assess the care needs in the community by receiving input from:
  - community
  - government
  - health care providers
  - persons with AIDS and their families
- recommend general organization for integration of care
- act as a think tank for innovative and cooperative services
- review evaluation results and recommend further changes as necessary

3.3.1.2 Representation

The intention of this level is broader than the usual planning model. The experience of San Francisco led the Working Group to feel strongly that planning and input must be from all levels of each community. If AIDS is to be effectively and positively addressed, there must be wide acceptance of responsibility. Suggested representatives include leaders from the fields of:

- volunteer AIDS groups
- public health
- community health
- hospitals -- acute and long-term care
- religion
- medicine
- nursing
- dentistry
- social work
- business/industry
- municipal government
- education

3.3.2 Coordinating Level

3.3.2.1 Function

- formulate a specific plan of action from the Planning Level's assessment of the community's needs and from input of intended provider groups
- develop an overall budget for a community AIDS program with appropriate allocation of funds to various provider groups
- request funding from appropriate governmental levels

- oversee evaluation measures

- ensure interagency and interdisciplinary communication and coordination among provider groups

3.3.2.2 Representation

Suggested representatives would be drawn from provider agencies and professional groups in the community.

3.3.3 Care Level

3.3.3.1 Function

- develop a plan of care on an individualized basis, ensuring that the patient and loved ones are involved in forming the plan and that their needs, as identified in Section 3.2.3, are fully considered

- designate one caregiver as the "primary care manager" to avoid confusion and unnecessary duplication -- this person could be a social worker, but may also be a nurse coordinator, physician or an AIDS volunteer depending upon the particular program, and would have frequent contact with other care providers

- implement specific segments of care

- work cooperatively with other segments

- communicate regularly with other segments

- implement evaluation procedures

- provide feedback to the Planning and Coordinating Levels

3.3.3.2 Representation

This level includes home care agencies, AIDS support groups, acute and long-term care institutions, palliative care programs, family service and social agencies, volunteer groups and so on.

The final line of Figure 10 further elaborates on the Care Level. The Care Level delivers the care within the framework of the overall community plan of care. As we learned from our research, this care falls into three major areas:

1. **Health Care** is provided by health care institutions (hospitals, nursing homes, palliative care facilities) or in the home (provincial home care programs, home nursing services, hospital home care programs). In all these settings, appropriately trained staff and adequate resources are required if high quality care is to be given. At present, we believe that there are adequate categories of care providers but that these workers must be used appropriately. *The Working Group also believes there is no need to develop new categories of health workers.*

2. **Community Support** may be provided by trained professionals or by trained volunteers. Community support can generally be divided into two types. **Emotional support** involves supportive counselling and requires specific training. This area also includes spiritual support either as outreach from local churches, or perhaps as part of a palliative care program or AIDS support group program. **Practical support** usually entails skilled help with the everyday activities of living at home, such as cleaning and shopping, meal preparation and assistance with personal care.

3. **Education** is an essential component of the Care Level. In anticipation of increasing numbers of persons with AIDS in each community, education of health care and social service professionals, and volunteers in hospitals and community programs is imperative to prepare caregivers for their work with persons with

AIDS. Education for patients and their loved ones in physical care is important to facilitate independent living. Public education programs about AIDS as a three-fold disease, about its impact on a community, and about prevention will also be necessary to relieve anxieties and prevent discrimination against persons with AIDS.

As described in Figure 10, all components of this care delivery model are necessary if integrated care is to be ensured. The number of people or agencies involved in care will depend on the size of the community and complexity of the appropriate network. The administrative aspects of the care delivery system must be flexible to expand according to changing circumstances in the community. Whatever plan the community adopts, certain factors must be taken into account:

- ability of existing palliative care programs to provide AIDS care
- necessity of multi-agency cooperation and how to foster it
- the role volunteers can play in delivery of services
- cost-effectiveness of services to be provided
- educational needs of the community about AIDS and educational needs of those with AIDS and their families
- level of government support available to care for persons with AIDS and their loved ones

We believe that an organizational arrangement as presented in Figure 10 allows for effective and integrated delivery of the wide range of services necessary to meet the needs of persons with AIDS and their families and friends.

Organizational structures similar to the Model of Care Delivery may already exist in some communities, while other communities are creating their own unique arrangements. *It is clear that pilot projects must be undertaken to demonstrate and develop models of care and models of care delivery for different communities across the country.*

3.4 Summary

Development of palliative care services for persons with AIDS and their loved ones is urgently needed. At present, only 10 to 15 percent of all terminally ill patients in Canada have access to palliative care services. Clearly, many new palliative care programs must be funded and established to meet the challenge of AIDS.

Supported by the survey findings and by data acquired from the site visits, we believe AIDS patients and their loved ones require a clearly definable set of palliative care services. *These services must be developed and delivered at the community level using a wide range of volunteer and professional caregivers and within an organizational structure which integrates the acute care, long-term care, palliative care and community systems into a fully coordinated care delivery system.*

To assist communities in developing their own AIDS care program, we have constructed a Model of Care which describes the needs of AIDS patients and who should deliver the services at various stages of the disease. To put this Model of Care into action, we have proposed a Model of Care Delivery which suggests a community-based organizational structure through which these services can be delivered. Within this framework, there is much room for sensitivity to local initiative. We were not intent upon proposing a single final model which every community should adopt. The needs and community structures are so diverse that this effort would be futile. Rather, we feel that, using the various threads of the bi-fold model we are proposing, communities can "weave" a model which best suits their

own local area and fully meets the needs of AIDS patients and their families.

There is a pressing need to develop these community-based organizations. The palliative care needs of persons with AIDS and their loved ones are immediate and will continue to grow in the foreseeable future. We cannot and should not wait.

Appendix I

The Facts about AIDS

Acquired Immunodeficiency Syndrome (AIDS) is an incurable disease caused by the Human Immunodeficiency Virus (HIV). This virus, discovered in 1983, infects and destroys the body's white blood cells, resulting in the development of profound immunodeficiency and extreme susceptibility to opportunistic infections such as *Pneumocystis carinii* Pneumonia (PCP) and a rare form of skin tumor known as Kaposi's sarcoma (KS).

HIV is transmitted through the exchange of certain body fluids; blood, semen and vaginal secretions have been found to pass on the virus. Sexual intercourse and sharing of intravenous needles are the principal ways in which HIV is transmitted. The virus can also be passed from mother to child either before or during birth.

Some people infected with HIV remain healthy and asymptomatic; others, for reasons yet unknown, develop HIV-related illnesses or severe neuropsychiatric dysfunction. The diseases of the AIDS patient, while not technologically demanding, are very labour-intensive.

Since the first case of AIDS was reported in Canada, the number of persons with AIDS has continued to increase. Current estimates are that 100,000 Canadians are infected with HIV.

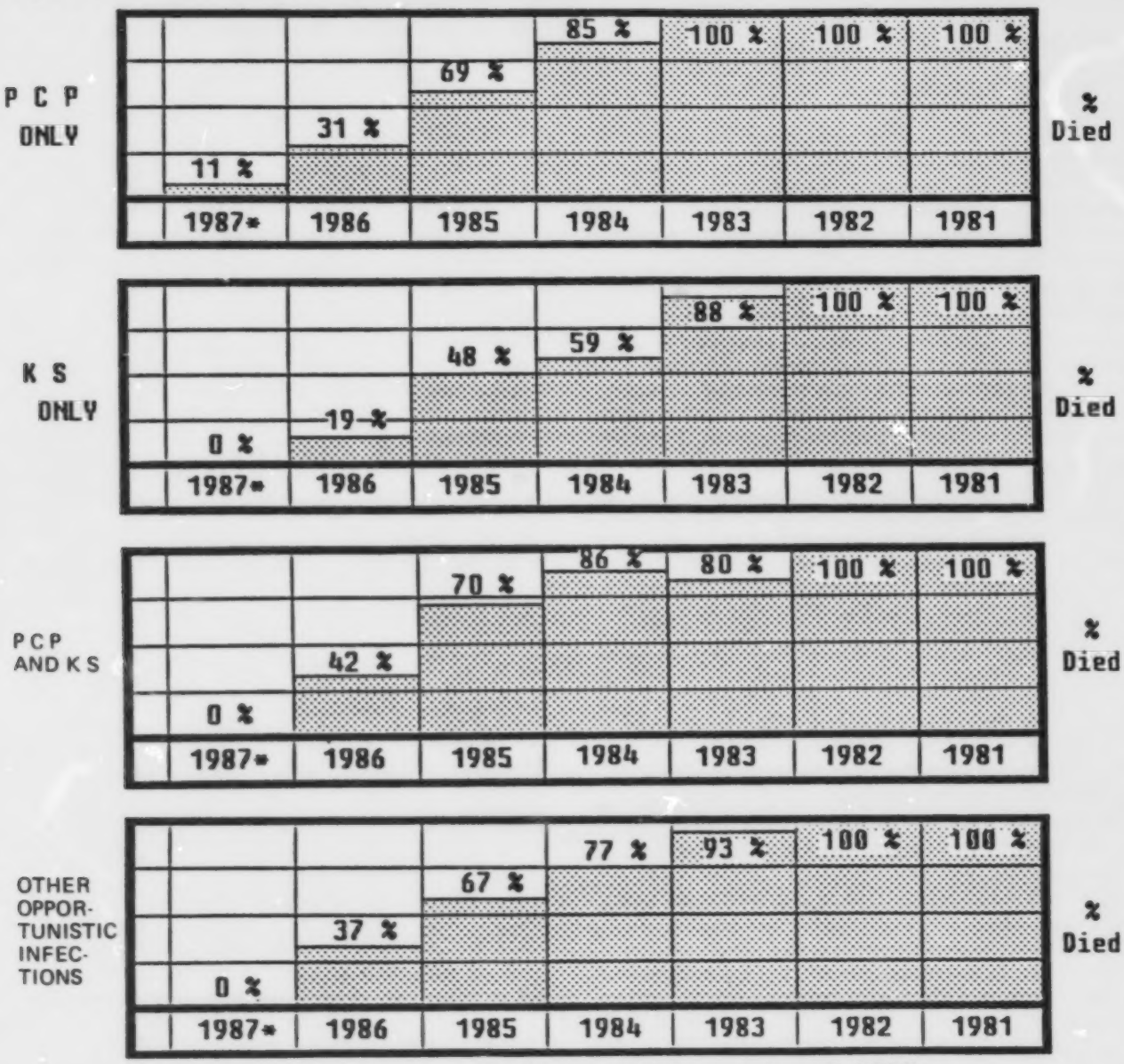
From 1981 (when AIDS was first reported) until August 1, 1987, the cumulative number of Canadians diagnosed with AIDS is 1,205, while the cumulative number of deaths totals 617. The mean life expectancy from time of diagnosis is usually not more than two years and is commonly nine months from the time of first hospitalization. Figure 11 illustrates the fatality rate among AIDS patients in Canada by different categories of infections to the end of March 1987[6]. It shows clearly the devastating nature of this illness.

The figures are somewhat different, albeit worse, for infants. As of August 4, 1987, 25 pediatric cases have been reported[7] -- 14 children (ages 1-14 years) and 11 infants. Ten of the infants have died (a staggering 91%), compared to eight of the children (57%) or 599 of the 1,180 adults (55%).

This mortality pattern may change as a result of treatment with experimental drugs. Canadians have been most seriously affected largely in the three major urban areas of Montréal, Toronto and Vancouver. Within the next few years, it is expected that there will be a decentralization of AIDS away from the major urban centres into smaller communities. This pattern is currently being observed in the United States, which epidemiologically is several years ahead of Canada with respect to the spread of HIV.

[6] Compiled for *Update: AIDS in Canada*, Laboratory Centre for Disease Control, Ottawa, April 6, 1987.
[7] Compiled for *Update: AIDS in Canada*, Laboratory Centre for Disease Control, Ottawa, August 4, 1987.

Figure 11: Fatality Rates in AIDS Care



* Jan.-Mar. By Year of Diagnosis of AIDS

Appendix II

Survey Results

Abstract

A survey was designed to elicit the experience of Canadians who had been caring for persons with AIDS. Results of the survey were intended to serve as one source of data for the Working Group on the Development of a Model of Integrated Palliative Care for Persons with AIDS. A two-part questionnaire was developed by the Working Group, to gather both quantitative and qualitative information about eight issues considered to be critical in the care of AIDS patients: symptom management, psychological support, interpersonal support, independent living, legal/financial support, lifestyle/cultural/ethnic/religious considerations, service delivery considerations and bereavement support. The Working Group identified four categories of potential respondents, and a targeted sampling approach was used to ensure that Canadians who had varying amounts of experience in caring for persons with AIDS were included in each category. Questionnaires were mailed to 160 agencies that indicated a willingness to participate.

A total of 84 questionnaires were returned, for a response rate of 52.5 percent. The respondents, drawn from every region of the country, included 27 hospitals, 28 palliative care programs, 15 home care/visiting nurse services, and 13 community-based AIDS groups. Respondents viewed provision of psychological support, including help in managing feelings of loss, anger and fear, as the most important issue in palliative care for persons with AIDS. The next most important issue these caregivers identified was the need for persons with AIDS to receive interpersonal support from parents and siblings, friends, lovers and caregivers. Service delivery considerations, including issues surrounding infection control, were ranked as third in overall importance. Symptom management was ranked fourth, with fatigue, oral care, dyspnea, and diarrhea identified as the important factors in AIDS care.

Although there were some differences in the perception of critical issues by type of program, the number of deaths experienced by the respondents appeared to be the central factor influencing their perceptions. The findings suggested a model of adjustment to involvement in caring for persons with AIDS. When fewer than three deaths had been experienced, health personnel and community members were still trying to master their own anxiety and learn about the disease so they could meet the challenge of providing care. As they acquired more experience, concerns about personal vulnerability decreased, and a sense of commitment to providing care to people with AIDS developed. However, once more than 10 deaths had been experienced, the respondents to this survey expressed concern about who was going to provide the volume of care required. Would only those who had already developed a commitment be left to cope with the ever increasing demand for services? Respondents identified the need to develop an integrated approach to service delivery in each community that would promote shared responsibility for care.

The survey also identified several questions for future research. What are the most effective strategies for providing psychological support to persons with AIDS, their families and friends? What are the most effective approaches to reducing the mental health risk for survivors of an AIDS-related death? What is the comparative effectiveness of hospital versus community-based models of care? How can professionals and members of the community at large master their own fears so they can provide compassionate care? These questions and others need to be answered if humane and effective palliative care is to be provided in Canada. Finally, a replication of this survey two years from now may provide useful insights into the changing perception

of needs as the AIDS epidemic spreads to all regions of Canada.

Acknowledgements

The project director would like to acknowledge the staff of the Manitoba Nursing Research Institute and the graduate students in the School of Nursing who contributed many hours to this project in addition to their usual work assignments. The contributors included: Sachi Eales, Administrative Secretary; Marie Sveistrup, Cathie Lamberd, and Ruth DeGraves, Research Assistants; Jeff Sloan, Statistical Consultant; David Gregory, Assistant Professor; and the following graduate students: Katie DeLeon, Lynne Giesbrecht, Laurie Thompson and Peri Venkatesh.

Mandate for the Survey

In October 1985, the Parliamentary Standing Committee on National Health and Welfare undertook a study of the major concerns and problems surrounding the issue of AIDS in Canada. Based on testimony from leading experts in the field of AIDS care, the Committee published the *Report on AIDS in Canada* in May 1986. This report contained 23 recommendations for national action on AIDS. Two of these recommendations were the formation of a committee to develop an integrated model of care for persons dying with AIDS, and the commissioning of a survey to determine the current status of AIDS care in Canada. The committee was subsequently established in November 1986, and was named the Expert Working Group on the Development of a Model of Integrated Palliative Care for Persons with AIDS. The members of the Working Group (see page 17) were selected by the staff of the National AIDS Centre and the Health Services and Promotion Branch of the Department of National Health and Welfare.

Purpose of the Survey

The survey described in this report was designed by the Expert Working Group as part of its mandate to develop a model of integrated palliative care for persons with AIDS, and in response to the recommendation of the Parliamentary Standing Committee on Health and Welfare. The purpose of the survey was to elicit the perspective of Canadians who had been involved in the care of persons with AIDS. The data generated by the survey was intended to serve as one source of information on which the committee would base its recommendations to the Minister of Health. Other sources of data included site visits to selected Canadian and American facilities caring for persons with AIDS, and the professional experiences of members of the Working Group.

The Questionnaire

A two-part questionnaire was developed by the Working Group using the following definition of palliative care as a guide:

Palliative care is defined as the active, compassionate care of the terminally ill at a time when their disease is no longer responsive to the traditional aims of cure and prolongation of life, and when the emphasis of care is on comfort and quality of life until death. Palliative care is delivered by a multidisciplinary team able to meet the physical, psychosocial and spiritual needs of the dying person and the family. In palliative care, both the dying person and the family are the unit of care, and care of the family extends after death has occurred.

The first part of the questionnaire requested demographic information about the nature of the respondent's program, while the second part asked respondents to

rate the importance of eight issues considered by the Working Group to be critical in the care of AIDS patients. These issues included:

1. Symptom Management

2. Psychological Support

3. Interpersonal Support

4. Independent Living

5. Legal/Financial Support

6. Lifestyle/Cultural/Ethnic/Religious Considerations

7. Service Delivery Considerations

8. Bereavement Support

Under each of these major issues, a number of subissues was identified. These subissues ranged in number from nine for symptom management, to four for interpersonal support and bereavement support. The respondents were asked to rate the importance of each subissue using a scale of one to five, with one representing "not important" and five representing "extremely important."

Respondents were also asked to provide qualitative data about their experiences in caring for AIDS patients. Written responses were requested for each of the following questions with respect to each of the subissues:

1. What specific strategies/resources have you used to address these issues in your program?

2. What difficulties/deficiencies have you encountered with respect to these issues?

3. What additional resources (number, types) do you need to address these issues adequately?

The questionnaire was pretested in two agencies in Winnipeg and translated into French for use in Quebec. A copy of the actual survey questionnaire is found at the end of this appendix on page 62.

The Sample

The Working Group identified four categories of potential respondents:

1. Hospitals

2. Palliative Care Programs

3. Public Health/Visiting Nurse Services

4. Community-Based AIDS Groups

A targeted sampling approach was used to ensure that Canadians who had varying amounts of experience in caring for persons with AIDS were included in each of these categories. The Working Group stratified potential respondents in each province by the estimated number of deaths experienced, and subsequently contacted key personnel in the selected agencies by telephone to elicit their interest in participating in the survey. Questionnaires were mailed to 160 agencies that indicated a willingness to participate.

Data Analysis

Demographic information and ratings supplied by the respondents were coded and entered into computer line files for analysis using SAS. The analysis included cross-tabulations of demographic characteristics; calculation of mean scores on the subissues and eight critical issues for the whole sample and selected subsamples; and calculation for the percentage of respondents that had ranked the subissues and eight crucial issues as "five" (the highest rating).

Qualitative responses were analyzed by the project director and seven research assistants using content analysis. Detailed summaries of responses to each of the eight issues were prepared using data from the first 25 questionnaires returned. Data from the subsequent 30 questionnaires were compared with the first detailed summaries to identify similarities and differences, and narrative accounts of the results were written. Qualitative information from subsequent questionnaires was integrated into these narrative descriptions by the project director as questionnaires were received.

The 20 questionnaires returned from Quebec were analyzed separately by a Francophone research assistant. Summaries of these data were prepared in the same manner. These summaries were then compared for similarities and differences with the descriptive summaries in English. Where similarities existed, the data were integrated into the narratives; where differences occurred, they were noted in the descriptions.

Findings

A total of 84 questionnaires were returned, for a response rate of 52.5 percent. Agencies that did not respond or returned questionnaires without completing them cited the time required to fill in the questionnaire and limited experience in caring for persons with AIDS as reasons for not participating. Those that did participate in the survey and indicated their agency type comprised:

- 27 hospitals
- 28 palliative care programs
- 15 home care/visiting nurse services
- 13 community-based AIDS groups

Respondents were drawn from every region of the country: 3 from the Atlantic provinces; 20 from Quebec; 37 from Ontario; 7 from the prairie provinces; and 17 from British Columbia. Most programs (80%) were located in cities with a population of more than 100,000 people.

The number of deaths of AIDS patients that had been experienced did not differ by type of program. Most programs (58%) had experienced three or fewer deaths, with 25 percent having 4 to 10 deaths, and 17 percent having over 10 deaths. The responding hospitals had been the first to care for patients with AIDS in 1976, with palliative care programs and community-based AIDS groups becoming involved in care in 1983, and the responding home care programs starting to care for patients in 1984.

Participants were asked to recall the location of death of the AIDS patients in their care. The vast majority of these deaths -- 356 of the total of 409 that the respondents could recall -- occurred in hospital. Only 53 deaths, or 13 percent, had occurred in the home environment. The experience of caring for dying AIDS patients captured by this survey represented most of which had occurred in Canada by the end of 1986, at which time a total of 634 AIDS patients are estimated to have died[8].

The amount of experience in caring for persons with AIDS is quickly increasing in Canada. Although the majority of programs had experienced 3 or fewer deaths, the number of patients that had been cared for were equally distributed, with 36 percent having cared for 3 or fewer patients, 35 percent 4 to 10 patients, and 30 percent over 10 patients. These data suggested that, given the limited lifespan of persons with AIDS, most programs will experience the deaths of at least 4 to 10 AIDS patients by 1988.

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[8]This estimate assumes a three-month time lag in reporting deaths. There may have been some double counting of deaths by agencies and community-based AIDS groups. The latter reported a total of 44 deaths.

Ratings of Critical Issues in Care: Quantitative Analysis

Table 1 summarizes the respondents' ratings of the critical issues in the care of AIDS patients. The respondents viewed providing psychological support, including help in managing feelings of loss, anger and fear, as the most important issue in palliative care for persons with AIDS. The next most important issue these caregivers identified was the need for persons with AIDS to receive interpersonal support from parents and siblings, friends, lovers and caregivers. Service delivery considerations, including issues surrounding infection control, were ranked as third in overall importance by the sample. Although symptom management (and pain management in particular) has received much emphasis in palliative care programs, respondents rated fatigue, oral care, dyspnea and diarrhea as the important factors in AIDS care.

The percentage of respondents that rated the critical issues as "most important" (5/5) was examined to reveal the urgency attached to each issue. Provision of psychological support maintained its position as the most important issue faced by caregivers, with 59 percent of programs giving it the highest rating (see Table 2). However, service delivery considerations and the need for bereavement support gained in importance when this method of ranking the critical issues was applied, indicating the urgency that respondents attached to these factors.

Table 1: Critical Issues in Order of Importance

Critical Issues	Mean
1. Psychological Support	4.14
a) Loss/Grief	4.65
b) Anger/Anxiety	4.49
c) Fear	4.45
d) Depression	4.37
e) Providing Affection	4.24
f) Loss of Self-Esteem	4.11
g) Guilt	3.77
2. Interpersonal Support	3.92
a) Relationship	4.68
b) Social Isolation	4.10
c) Discrimination	4.00
d) Loss of Anonymity	3.57
3. Service Delivery Considerations	3.77
a) Infection Control	4.41
b) Staff Support	4.30
c) Role of Patient	4.26
d) Facilities	3.61
e) Administrative Concerns	3.66
4. Symptom Management	3.41
a) Fatigue	4.12
b) Oral Care	3.79
c) Dyspnea	3.70
d) Diarrhea	3.68
e) Skin Breakdown	3.52
f) Nausea	3.51
g) Pain	3.46
h) Dementia	3.27
i) Loss of Vision	2.64
5. Bereavement Support	3.38
a) Family Residing Locally	4.16
b) Lover Residing Locally	4.00
c) Family Residing at a Distance	3.57
d) Lover Residing at a Distance	3.23
6. Independent Living	3.14
a) Home Support Services	4.18
b) Home Nursing Care	4.08
c) Respite Care	4.03
d) Coordination of Care	3.97
e) Special Accommodations	3.26
f) Employment	3.06
g) Transportation	2.83
h) Day Care	2.51

7. Legal/Financial Support	3.14
a) Patients' Rights	4.40
b) Funeral Arrangements	3.61
c) Income Sources	3.51
d) Wills/Attorney	3.20
e) Employment	2.96
8. Lifestyle Considerations	2.80
a) Gay Lifestyle	3.74
b) Homophobia	3.38
c) Death/Funeral/Spiritual Customs	3.26
d) Drug Subculture	2.59
e) Prostitution	2.43

Table 2: Percentage of Respondents Ranking Core Issues as 5/5 (Most Important)

Issues	Percentage
1. Psychological Support	59%
2. Service Delivery Considerations	49%
3. Interpersonal Support	48%
4. Bereavement Support	39%
5. Symptom Management	35%
6. Independent Living	31%
7. Legal/Financial Support	29%
8. Lifestyle Considerations	22%

Community-based AIDS groups gave the need for psychological support the highest mean rating, followed by home care programs and hospitals (see Table 3). The perceived importance of providing both psychological and interpersonal support increased as respondents experienced more deaths of AIDS patients (see Table 4). At the same time, the importance of service delivery considerations decreased with an increasing number of deaths.

Home care and visiting nurse programs viewed the subissue of "infection control" as extremely important, as did hospitals (see Table 5). "Providing affection" was a subissue of particular importance to community-based AIDS groups. As might be expected, home care programs rated the subissue of coordination of care and home nursing care as extremely important, while the need for respite care was a particular concern for palliative care programs.

The perceived importance of infection control decreased once respondents had experienced at least three AIDS-related deaths, but increased in importance again after more than 10 deaths had occurred (see Table 6). A similar trend was found with respect to the need for staff support. The importance of dementia as a management problem increased dramatically as programs cared for increasing numbers of persons with AIDS. Similarly, the importance of homophobia as a factor influencing the care of persons with AIDS increased substantially as the numbers of deaths increased.

Summary of Quantitative Issues

Responding agencies rated the issues of psychological support, interpersonal support and service delivery considerations as most important in caring for people with AIDS. Some differences existed in the ratings by type of agency, but the number of AIDS-related deaths experienced was particularly important in influencing perceptions of the respondents.

Table 3: Ratings of the Three Most Important Issues by Type of Program

Issue	Hospital (n-26)	Palliative Care Program (n=29)	Home Care Program (n=14)	Community-Based AIDS Groups (n=13)
Psychological Support	4.19	3.90	4.20	4.44
Interpersonal Support	3.84	4.10	3.81	3.85
Service Delivery Considerations	3.65	3.83	3.83	3.72

Table 4: Ratings of the Three Most Important Issues by Death Experience

Issue	3 or less (n=39)	4-10 (n=17)	More than 10 (n=13)
Psychological Support	4.06	4.07	4.36
Interpersonal Support	3.74	4.10	4.08
Service Delivery Considerations	4.05	3.27	3.44

Table 5: Ratings of Selected Subissues by Program Type

Subissues	Hospital	Palliative Care Program	Home Care Program	Community AIDS Groups
Infection Control	4.74	4.28	4.86	3.73
Providing Affection	4.39	4.24	3.57	4.82
Coordination of Care	3.43	3.95	4.62	3.75
Respite Care	3.53	4.50	4.23	3.41
Home Nursing	3.95	3.86	4.69	3.82

Table 6: Ratings of Selected Subissues by Death Experience

	Number of Deaths		
Subissues	3 or less	4-10	More than 10
Infection Control	4.72	3.88	4.55
Staff Support	4.62	3.71	4.08
Dementia	2.83	3.44	4.09
Homophobia	2.97	3.35	4.18

Critical Issues in Care: Qualitative Findings

Although 84 questionnaires were returned, written responses were provided by only 48 agencies or 57 percent of respondents. Most of those who commented wrote extensively about their experience in caring for AIDS patients. As a result, this qualitative description of the eight critical issues identified by the Working Group provides a detailed picture of the experience to date in caring for people with AIDS. The challenge of providing compassionate care is one that Canadians are responding to, but not without concerns for the future.

I. Psychological Support

Respondents identified their major strategies to provide psychological support for patients, families and friends. These resources were primarily supportive and educative counselling services offered by:

- a multidisciplinary team including: nursing, medicine, pastoral care, social work and psychiatric services
- volunteers, self-help groups and one-to-one buddy systems
- the palliative care team and respite care

Early referral to these services was identified as a key strategy to develop trust and rapport with clients and families. Automatic referral to these services upon diagnosis was recommended to prevent delays in meeting these needs. Other strategies included: open visiting hours, a phone line, newsletters and printed information material to maintain a link between the community and hospital.

Generally, difficulties and deficiencies encountered centred around the attitudes of the family, caregiver and patient toward the disease, and the lack of knowledge regarding resources. Environmental constraints influenced implementation of services. For example, the number of private rooms available decreased with the increasing number of persons with AIDS, and often there were no family meeting rooms in the setting.

Limitations in numbers, time and knowledge level of human resources were identified as the major deficiencies. Lack of client follow-through with support groups was also indicated as an area of difficulty. Many clients were unwilling to discuss psychological issues in support groups due to fears regarding anonymity. Family dysfunction was a common theme, and was related to family's non-acceptance of the disease and the gay life-style. Many significant others were reluctant to seek referral, and alcohol abuse among family members was encountered. The difficulty faced by families in dealing with their own anger, anxiety and fears posed problems with displaying affection and providing psychological support. Limitations on visiting privileges also posed difficulties for the family in providing support to the patient.

Specifically, the deficiencies in providing psychological support were identified as:

- lack of immediately available, low-cost professional services
- lack of integration among existing services
- lack of supportive mechanisms for professionals providing care to persons with AIDS
- lack of hospital-based support groups for persons with AIDS
- lack of hospice care for persons with AIDS
- lack of education for the auxiliary staff

A variety of additional resources was suggested to improve the quality of psychological care. These

resources included education for staff, family and the patient centred on sexuality and human relationships; well-advertised community support groups; support groups for significant others and caregivers; family counselling services; volunteer programs for visiting vigils; psychological and psychiatric services; nation-wide networking system with gay communities and resources for information exchange; liaison between community services and the gay community; increased pastoral care and social services; specially trained paramedical personnel who have interests in this area; patient advocates; occupational, physical and music therapists; addiction counsellors; inservices for nursing staff about psychological coping mechanisms; additional staff to meet counselling needs; buddy system between clients; and non-traditional resources such as psychic healing, biofeedback, relaxation, recreational and music therapy.

Several specific components of this issue were noted by respondents.

1. Grief/Loss: Compounded grief is experienced by persons with AIDS due to loss of many friends. Bereavement counselling was identified as a needed resource for the person with AIDS.

2. Anger/Anxiety: Family's inability to resolve anger poses difficulty in providing psychological support. Persons with AIDS frequently express anger outward to staff. A frequent source of anxiety includes the physiological symptoms experienced by the persons with AIDS. Effectiveness of psychological care is influenced by the degree to which symptoms are managed.

3. Affection: This component received much discussion. Difficulties were faced by caregivers and family in displaying affection due to their own fears and anxieties. Constraints were posed by the isolation protocol. Role modelling was identified as a strategy to deal with this area.

4. Fear: Staff selection was identified as a concern. Allowing staff choices to care or not care for persons with AIDS was identified as a strategy to decrease fear among caregivers. Policies, procedures and learning packages for staff were identified as possible solutions to this problem. Lack of agreement among health providers was identified as a source of fear for the patient. In addition, many caregivers were unable to deal with the patient's fear of dying. Family members also had difficulty expressing their fears.

5. Self-Esteem: Strategies to maintain independence with activities of daily living were effective in reducing loss of self-esteem. Difficulties arose when persons with AIDS were unable to continue self-care.

6. Depression: Use of anti-depressants and drugs (marijuana) was identified as a strategy to deal with depression. Suicide was identified as an alternative. Many staff members had difficultly dealing with this area.

7. Other: Other components identified under this core issue were: denial; religious needs; changes in mental function and personality of the persons with AIDS; and impact of the diagnosis of terminal illness. Night management was identified as a problem due to lack of staff to deal with psychological needs which manifest themselves more severely at night.

French-speaking respondents identified a critical problem: lack of support for Haitians and heterosexuals. Neither of these groups have the well-developed support system that homosexuals have, and Haitians in particular are neglected. Increased support within the culture was identified as a potential solution.

II Interpersonal Support

1. Support from Significant Others

The role of significant others (i.e., families, lovers and friends) in offering emotional support was overwhelmingly identified as important. Potential support available to the patient from these individuals was deemed as a crucial area requiring assessment. Extensive explanations about contagion, prognosis and symptom development could be the key to gaining support of significant others for the patient. Maintenance of existing relationships with significant others was noted as a necessary element to provide emotional support and minimize social isolation for the person with AIDS.

Formation of self-help groups and the use of existing community groups were suggested as strategies for support. Problems associated with support groups included: diagnosis of AIDS becomes known in the public sector; and some patients may not want to make use of the groups (e.g., support groups emanating from the gay population). AIDS patients who had worked through and adjusted well to their situation were seen as valuable resource persons in counselling other AIDS patients.

a) Involvement of Clergy

Survey respondents suggested that clergy possess a significant role in offering spiritual support to AIDS patients and family members. Several AIDS patients were noted as experiencing spiritual dissonance.

b) Family-Related Concerns

Respondents identified the need to develop and maintain open communication with family members. Meetings with family members, with and without the patient, were advocated to promote communication and understanding. The family was noted as requiring support throughout the illness and after the death of their loved one. Persons with AIDS were reluctant to share their diagnosis with family members and other significant persons because they feared abandonment and rejection. Several institutions found it necessary to assist AIDS patients to share their diagnosis and situation with significant others. Many AIDS patients purposefully isolated themselves from staff and significant others. Having friends divulge their diagnosis in the public realm was a concern to many persons with AIDS. AIDS patients who relocated to larger centres for treatment (or to maintain anonymity) were often without their previously established support systems.

c) Education

Lack of education regarding AIDS was noted on the part of AIDS patients, family members and significant others, health care personnel and communities. Lack of education and the need for augmented educational services was emphasized repeatedly. The following areas were viewed as requiring further clarification and development: disease etiology; communicability of AIDS; treatment; isolation requirements and techniques; sexuality; educational resources; patient's rights; and the public's understanding of the disease. Prejudices and negative attitudes result in suffering for all those providing care and support to the person with AIDS. The media was identified as creating a panic state about AIDS that was alarming people excessively.

d) Confidentiality and Discrimination

Extended family members were suggested as being most discriminatory against the AIDS patient. Staff refused to work with AIDS patients for the following reasons: religious convictions; fear of contracting AIDS; lack of knowledge regarding AIDS; homophobia; spouse's fear of contracting AIDS; and prejudice and moral judgments about AIDS. Gossiping among hospital personnel was a problem and there was a tendency of staff to assume that

persons with AIDS are automatically homosexual. There was also a sense of prestige associated in caring for a person with AIDS and a tendency to be vocal about this type of patient assignment. Smaller communities tended to discriminate more and confidentiality is a real problem. Patient referrals to adjunct agencies such as Victorian Order of Nurses and home care often required the patient's name and diagnosis to be divulged. Persons with AIDS were identified as being quite sensitive to the care they received and perceived discrimination from staff as painful. Several strategies were suggested to combat discrimination: hospital/institution policies; education of health care professionals in clinical and educational settings; involvement of the human rights commission; lobby groups; and provincial/federal legislation. To ensure confidentiality, the following specific strategies were suggested by the respondents: labelling of specimens with codes; hospital policy regarding confidentiality; and explaining to the patient the realities of the health care system (total confidentiality is difficult to maintain). Conflict exists between the spreading of the epidemic and the anonymity of its victims.

e) Service Coordination

The need to coordinate existing services (health and social) to ensure comprehensive care was repeatedly mentioned. A care coordinator position was suggested, and this person would function in a liaison role with respect to: educational resources; support groups, both professional and nonprofessional; counselling services; and networking with large resource centres. Collaborative efforts among the various support groups are needed since no one group will be able to provide all necessary support.

f) Strategies for Care

A conflict or a sense of competition appears to exist between certain strategies in providing patient care. For example, the desire to promote social interaction in AIDS patients conflicts with use of a private room. Strategies for care suggested by the respondents included: limiting the number of health care professionals interacting with the patient; assigning a "core group" of caregivers for persons with AIDS; holding support meetings for staff members; accommodating the patient's preference of caregivers; communicating openly with family, friends and relatives; involving support groups; using volunteers and surrogate friends; holding patient conferences; and establishing the patient's wishes before dementia develops. Control of sensationalism in the media was an additional strategy that could improve the interpersonal support available to persons with AIDS. Once again, respondents from Quebec identified a great deficiency in support and care for friends and families of Haitian AIDS victims, as well as a complete absence of special support for young children related to the AIDS patient.

III. Service Delivery Considerations

1. Role of Patient with the Natural/Acquired Family in an Ongoing Plan of Care

Family involvement was valued and encouraged by respondents. Frequent references were made about the importance of communication and consistency in approach, particularly in view of discrepancies seen between family and staff perceptions and between acquired and natural families' perceptions. Patient wishes were identified as the guiding force for the plan of care. Particular strategies outlined included hospice care: teaching families how to care for the patient; reassessing their adherence to technique on a periodic basis; a communication book for visitors to communicate with one another; and multidisciplinary conferences with families. Conflicts between the patient, the natural family and the acquired family complicated decision making. Isolation of the patient as part of the treatment was sometimes misinterpreted by families as neglect.

Additional needs included support groups for family and friends; a liaison between patient, family and hospital staff; and quality home care and social services.

2. Infection Control

Education of health care workers and the community regarding specific guidelines for body fluid precautions was stressed repeatedly. Examples of specific approaches which have proven effective included colour-coded arm bands for patients on precautions; disinfecting needles prior to disposal; and monitoring of white blood cells. It was suggested that a clinical nurse specialist coordinate follow-up. Inconsistent adherence to policies and procedures, and a persistent lack of knowledge contributed to difficulties with infection control. Staff turnover and relief staffing contributed to this lack of consistency. Additional resources included better guidelines for home management; in-hospital disinfection of equipment such as fibreoptic scopes; more professional literature; and videos on the management of AIDS. Respondents stressed that maintaining proper infection control is expensive.

3. Staff Support

Emotional support for caregivers is perceived as necessary, and suggestions to address this need include a staff support group, educational workshops with videos such as "AIDS: A Family Experience," and input from a nurse clinician. There was concern expressed over staff burnout related to the lack of time for grieving because of heavy caseloads. Staff are concerned about varying views in ethical decision making. Suggestions to reduce staff stress included dilution of caseload and more flexible working hours for caregivers. Physicians and head nurses were identified as important role models for other staff members.

4. Physical Facilities

Most centres admitted patients to specific units with a single room. Patients had discretionary use of the public area. There was concern expressed regarding scattering of services for both home and hospital settings. Difficulties encountered at home included problems with garbage disposal, laundry facilities and the protection of furniture from body fluids. Patients needed more space for socializing in the hospital. A need for specialized units or hospice care with more private family rooms was identified.

5. Administrative Concerns

Administration has taken responsibility to initiate and carry out special programs, policies and procedures. There may be a hospital coordinating committee with involvement of community services. One centre indicated that it screened staff regarding their attitudes about working with persons with AIDS before hiring. Administrative difficulties included: dealing with the media; maintaining confidentiality; predicting the demand for staff/services; funding; providing moral support for staff; and lack of formal policies and procedures. One respondent referred to the use of pseudonyms for AIDS and the resulting communication problems. Clients often do not have the coverage for a private room, thus increasing the financial drain on the institution. Further suggestions included relief staffing; increased education and staff support. Consideration was given to screening employees for AIDS. A need was seen to publish a prototype of terms of reference and objectives for hospital committees to enhance national consistencies in the management of persons with AIDS. Because of the extraordinary costs of treating these patients, it was suggested that a special representative be sent to the provincial and federal ministers of health to examine the type of finances needed to give quality care.

IV. Symptom Management

1. Pain

Pain appeared to be manageable with the use of medication (morphine sulphate being the drug of choice), and consultative support from professional services such as a pharmacist, pain clinic, pain management physician and hospice personnel. Hypnosis, massage, imagery, environmental considerations and emotional support were noted as important adjuncts in pain management. Training in pain assessment and management for volunteers and families was also noted as an effective measure. Difficulties were encountered because of lack of understanding of the pathology of pain among health care workers. For the patient being cared for at home, the lack of funding and of available narcotics at local pharmacies created difficulties. Problems were encountered because patients did not ask for pain medication, were afraid of addiction, or had a history of drug abuse. Respondents suggested the use of standard care plans and standing orders for pain medication. Better use of hospice consultants was recommended, as well as an actual palliative care program to assess the symptom. Assistance for the patient at home might be achieved by having an on-call pharmacist and emergency courier service for medications, and appropriate personnel to make home visits. Physicians sometimes lacked knowledge about appropriate drug dosages and, as a result, did not support requests from community nurses to increase dosages. Respondents from Quebec identified that detoxifying drug-addicted patients is essential to pain management, yet there is a lack of expertise regarding detoxification.

2. Dementia

Dementia was not reported as a frequent problem, but did create major management problems when it occurred. Popular strategies included interdisciplinary team approaches which incorporated psychiatric input, thorough investigation for underlying pathology or drug-related causes, and emotional support from volunteers and family. Dementia is extremely difficult to manage at home and especially draining on family, friends and home care workers. Major concerns included security of the home and hospital environment, and maintaining isolation protocols. Again, lack of understanding among medical personnel was expressed as a major concern. Teaching that dementia is caused by the virus can increase acceptance of the problem. Further suggestions included neurological and psychiatric consultations, and a care plan developed collaboratively with psychiatry. Personnel who are competent to deal with AIDS-related dementia and effective medications are needed.

3. Diarrhea

Diarrhea was a frequent symptom, and was managed with diet and medication. Diarrhea necessitated the use of strict isolation technique with very specific enteric precautions, and thus an increased drain on supplies such as linen and diapers. Staff fear of AIDS led to deficiencies in care. Family cooperation with care of excreta and linen was crucial. Diarrhea created further problems of embarrassment, dehydration, skin breakdown and infection. Families may be reluctant to care for patients with diarrhea and may lack supplies and knowledge to do so. Often, patients refused Lomotil as treatment for the diarrhea since it increased abdominal pain and shortness of breath. Education regarding isolation technique was seen as very necessary. These patients needed improved room facilities with a separate bathroom and bathing facilities. Many respondents stated that this symptom is unmanageable, untreatable and frustrating.

4. Dyspnea

Dyspnea is not frequently a problem, but requires admission when present, for oxygen therapy and

possibly admission to ICU. Decision making regarding resuscitation and continued life support raises both ethical and legal issues. These patients may need assistance in adapting the home environment and using equipment such as portable oxygen since increased debility makes home management very difficult. A need was identified to study effective sterilization of respiratory equipment (ventilators) used on AIDS patients. It was suggested that legal counsel be available to deal with ethical issues.

5. Oral Care

These patients need frequent mouth care, but basic nursing care prevented major complications. Suggestions included: brandy and water; an oncology mouthwash; anti-herpetic solutions; and Mycostatin for thrush. Technique for giving mouth care included consistent use of gloves. Patients may become indifferent to their oral health due to the demoralizing effects of treatment. However, once patients lost their ability to speak and eat due to advanced oral problems, their interest in oral hygiene improved. Dentists were consulted as necessary, although a general reluctance exists among dentists to work with patients with AIDS. It was suggested that more home care hours would help provide the frequent mouth care required. A special dental clinic was suggested.

6. Loss of Vision

Many patients have not experienced this problem, but it creates panic and loss of autonomy when it does occur. Resources have included ophthalmologists and the CNIB. The CNIB has been reluctant to become involved as the lifespan of these patients is usually too short for them to learn the skills taught by the CNIB. Staff often overlook the vision deficit, and need to be alerted to its occurrence. Concern was again expressed regarding centralization of services to manage this problem. It was suggested that there be increased education of CNIB personnel and optometrists.

7. Nausea

Nausea is manageable with anti-emetics, diet and basic nursing care. Cessation of nausea-inducing drugs and parenteral medications provides some relief. The major deficiency is the lack of effective anti-emetics. Mutual support at mealtime was found to be useful. Although sometimes difficult, enteric precautions are observed with the emesis. Medication routes have also presented problems if nausea persists. Increased dietary involvement was suggested.

8. Fatigue

Fatigue can be an overwhelming problem, especially in late stages of the disease. Patients need physical support and psychological stimulation to reduce fatigue. Frequent naps and mattresses designed for greater comfort were suggested. Fatigue makes it difficult for people with AIDS to remain at home because of the lack of 24-hour home support services which are necessary. For patients in hospital, the extreme fatigue increases the work load for staff. Resources in the form of a coordinator of volunteer services, a pool of nurses to work with AIDS patients, and supervised housing were suggested.

9. Skin Breakdown

This symptom seems to be more common in the late stages, and is managed by basic nursing care, topical medications prescribed by dermatologists, and the use of appropriate equipment such as eggcrate mattresses. Proper technique is required in dealing with drainage. Skin breakdown is very hard to treat, and the condition usually worsens in spite of treatment. Equipment costs are high, and fluid precautions are a persistent problem. Resources such as financial help for equipment and a

standard teaching plan for staff were recommended. Skin breakdown further erodes patients' self-image since they may be treated like lepers. Staff may experience accentuated fears of contagion and feelings of repulsion when caring for patients with skin breakdown.

10. Other

There were a number of other symptoms outlined. The most frequent was anorexia and associated weight loss, which was managed with input from family and dietitians. Management did not appear to be successful, however. Other symptoms included: impaired mobility; fungal infections of the toenails; rectal lesions; night sweats; neurological complication (i.e., seizures); gastro-intestinal bleeding; constipation; hair loss; nasal rhinitis; and skin discoloration. The respondents reported problems in finding specialists (e.g., anesthetists) who were willing to assist in managing these problems.

V. Bereavement Support

1. Family Residing Locally

A number of resources have been used to provide bereavement follow-up to this "high risk" group of survivors. These supports include: pastoral care; palliative care programs; social workers; buddies; volunteers; trained counsellors; group therapy; public health or primary care nurse; referral to AIDS support groups; attendance at funeral/memorial services; telephone contact; and printed information. Several difficulties have been encountered in providing bereavement support, including social stigma, which leads some families to be secretive about the cause of death and as a result they close off friends and neighbours as a source of support; physicians won't refer to a palliative care program where bereavement support is available; and lack of sufficient resources. Potential solutions include a paid staff coordinator providing bereavement follow-up and bereavement support groups set up by the gay community. Families may need separate bereavement support from that provided by palliative care programs because of their reluctance to disclose details of the loss. A variety of services could be integrated into a regional bereavement network. However, a major problem is lack of funding for bereavement follow-up (e.g., only one visit may be funded).

2. Families Residing at a Distance

These families can be referred to local AIDS committees or bereavement follow-up programs, and/or contact can be maintained by phone calls and letter writing. Several problems are encountered: families often did not know the patient was gay or ill; families may be reluctant to seek local support; and local personnel may not be trained in AIDS-related issues. Strategies suggested were a paid staff coordinator, and a national inventory of readily available support groups (both AIDS and grief-related).

3. Lovers/Friends Residing Locally

Strategies included showing equal respect to lover and family, and providing counselling. One problem is that the lovers have specific concerns (e.g., fear of acquiring the disease) which do not fit well with other grief-recovery groups. Another problem is that conflicts can arise between the lover and the patient's family.

4. Lovers/Friends Residing at a Distance

Strategies included referrals to local AIDS and bereavement follow-up programs, and sending out information packages. Problems were encountered in contacting these people, and the local programs were not trained in AIDS-related issues.

VI. Independent Living

1. Need for Special Living Accommodation

While special living accommodation has not constituted a significant problem to date, there is concern that it will be a major issue in the future. Patients have been able to receive care at home or in hospice, but several deficiencies have been noted. Family members and other people in the community may be reluctant to take AIDS patients into their homes or facilities; there are no appropriate transitional facilities between hospital and home; and there are already long waiting lists for subsidized accommodation. As a result, there may be inappropriate use of acute care beds for AIDS patients who could be managed in the community. AIDS-specific hospices were identified as one potential solution; as were halfway houses; self-help groups; Shanti type housing; group homes; or multilevel care facilities. Respondents emphasized the need for funding such specialized facilities.

2. Coordination of Care

Several strategies were used to address coordination of care including: hospital liaison programs; teams that visit patients both at home and in hospital; hospice programs that provide guaranteed admission; contacts with primary physician; discharge planning conferences; and family conferences. Specific problems that were encountered included: inadequate information to plan care due to confidentiality; lack of time to adequately plan for discharge; people afraid to take patient home; and for the patient, the trauma of each transition marking a further loss. A potential solution might include hospices that provide safety and stability.

3. Respite Care

Strategies included use of volunteers and AIDS-support group members; intermittent readmission to hospital; admission to hospice; buddies to give caregivers respite; pools of families, friends and colleagues that spell each other off; homemakers; and private nursing agencies. Problems encountered included: tensions between gay and straight caregivers; providing the amount of support required by volunteers; insufficient home care staff; patient's refusal of outside help including institutionalization for respite care; family's reluctance to let anyone else provide care; and exhaustion of family and friends. Additional resources are needed, including respite beds for AIDS patients in established facilities; volunteer sitters in the home; lodge facilities for out-of-town caregivers; and income replacement for family caregivers. Respondents from Quebec reported that no respite care really exists for persons with AIDS.

4. Home Nursing Care

A variety of home nursing services was used, but there was also reliance on family participation in care. Very critical deficiencies were identified in this area. Insufficient numbers of home care staff who were available for an insufficient number of hours (e.g., lack of "shift care," particularly at night) appeared to be the major problem. However, cost of providing care 24 hours a day was recognized as being prohibitive. Another major problem was that home care workers and their spouses were uncomfortable about working with AIDS patients, and little inservice, psychosocial support or written materials were available to help address this issue. The obvious solution identified by respondents was improved training and funding for home care services.

5. Home Support Services

Homemakers; meals on wheels; buddies who help with cleaning, laundry and shopping; and volunteers--all are important resources. A major problem is that most volunteers have day jobs, yet their services are required over extended periods of time. Inadequate availability of specialized support services was also identified as

problematic (e.g., services to care for implanted venous access devices; physiotherapy/occupational therapy services). Problems also arose with availability of equipment when agencies were not aware of decontamination procedures. Public education was identified as a potential solution in this issue.

6. Day Care

Most respondents did not view this resource as one needed to date. However, a few respondents thought that it was an important future strategy for caregiver respite and to decrease pressure on acute care beds.

7. Employment

The majority of persons with AIDS are unable to work due to severity of illness and the associated fatigue and, as a result, require help to fill out applications to get financial assistance. Most employers are not told about the AIDS diagnosis because of fears about the disease among both employers and employees. Employers who emphasize high productivity have little use for persons with AIDS since they frequently require days off or even extended leave. Many patients with AIDS have been dismissed when the hospital has informed the employer about the patient's diagnosis. Difficulty can arise in scheduling treatments for those patients who are working, unless evening services are available or occupational health nurses become involved. However, such services are important because patients who remain active and involved in life tend to maintain a high quality of living as the disease progresses. AZT was seen as a medication to increasingly help patients function in the employment setting.

8. Transportation

Patients are too weak to use public transportation, but since taxis are prohibitively expensive, they require assistance from family, friends or volunteers, or else access to taxi vouchers. Problems can arise if the patient is unwilling to contact the local AIDS society to get assistance with transportation. Problems can arise with ambulance personnel who are not aware of infection-control protocols and, as a result, overreact when transporting patients with AIDS.

VII. Legal and Financial Support

1. Sources of Income

Respondents identified that hospital social services were used extensively. Major sources of income for patients with AIDS included disability pension, extended health benefits, unemployment insurance, Canada Pension Plan and family support.

Support groups played an active role in assisting persons with AIDS to secure funding. Physicians and social workers sometimes informed patients inadequately about available resources. Quick resolution of financial and legal concerns was suggested given the rapid progression of the disease. Some of the difficulties associated with sources of financial income included: patients' reluctance to apply for disability pension/ unemployment insurance for fear of diagnosis becoming public information; bureaucratic impediments obstructing legal, social and financial assistance; existence of inadequate funding sources; and lack of emergency-funding sources available to persons with AIDS.

Patients are usually without adequate financial resources because of their youth and, as a result, it is very difficult to maintain their usual quality of life. Several respondents suggested that all costs should be covered be government.

2. Funeral Arrangements

Funeral arrangements were frequently discussed with AIDS patients which resulted in some persons planning their funerals. This area was identified as potentially volatile because of the possibility of conflicts among patient, family members and lovers about different funeral plans. In many instances, no prior funeral arrangements were made because of the AIDS patient's youthfulness. There appeared to be significant interaction between the health care facility and funeral home operators. Many funeral home directors refused to accept bodies of AIDS patients for fear of developing AIDS as a result of the embalming procedure. A clear majority of respondents suggested that funeral home directors need to be educated about AIDS, acceptable procedures for embalming, and disposal of the body (e.g., some of the bodies of AIDS patients were not embalmed and were quickly cremated). Standards for funeral homes were identified as necessary. Some health facilities developed a pamphlet for patients which outlined the necessary steps and procedures involved in funeral arrangements. In many instances, a list of funeral homes accepting the bodies of AIDS patients was formulated by health care facilities. There was often such great haste to get rid of the bodies of persons with AIDS that, in some cases, cremation had occurred before the family had a chance to take part in decisions and ceremonies. Education about decontamination procedures was identified as a critical issue for the funeral home industry.

3. Wills

Several agencies referred AIDS patients to legal services, legal aid, or hospital legal advisors. The family was suggested as the agent to assist the patient in the drafting of a will. Legal counselling at the time of diagnosis was suggested as very important for the person with AIDS because of the high risk of mental deterioration as the disease progresses. Conflict can develop between the family and lover of the person with AIDS. Due to the nature of a homosexual relationship, no legal contract exists. Difficulty in finding lawyers willing to work with AIDS patients was noted. Health care providers stated they had some discomfort with the impending death of young AIDS patients and, consequently, did not discuss matters related to funeral arrangements or making a last will and testament. Similarly, the patient may be reluctant to sign a will because it heralds death. The social worker was frequently identified as the health care worker who took charge in this area. In addition, staff education with respect to counselling patients on legal affairs and availability of low cost legal services was recommended.

4. Patient's Rights

Respondents emphasized the importance of assisting patients to make decisions about their own care. However, medical specialists did not always provide sufficient information about the prognosis and the side effects of treatment for the patient to make an informed choice. Support groups were identified as patient advocates, and patients were usually informed of their rights by the facility staff. There was a strong emphasis on confidentiality and the facility's policy about this subject. Keeping the client well informed was paramount. Violation of the patient's rights was indicated by several health care institutions (e.g., sharing the client's diagnosis without consent). Testing for the AIDS virus should require consent, and it was suggested that legislation was needed in this area.

5. Ethical Issues

As assortment of legal/ethical issues was identified by the respondents:

- resuscitation/non-resuscitation of young AIDS patients
- dilemmas regarding advanced life support

- experimentation of persons with AIDS
- conflict between the patient and significant others regarding treatment
- AIDS diagnosis on employment separation records
- not informing the patient or significant others of the AIDS diagnosis

6. Employment/Employers

Job retraining and an employment network were suggested as necessary strategies for AIDS patients. Variability of support among employers with respect to employees with AIDS was identified. Respondents stressed the need to educate employers.

VIII. Lifestyle/Cultural/Ethnic/Religious Considerations

1. Gay Lifestyle/Homophobia

The main strategy used to address these issues was individualized, non-judgmental care. Emphasis was on AIDS as a health problem versus a gay problem. Education was provided to staff, caregivers and the public regarding gay lifestyles and safe sex. Support to patients was provided through friends, AIDS support groups and the gay community. Support staff and family were also important, but resources in these areas were considered deficient. An interdisciplinary approach was stressed. Role-modelling for staff by gay staff has been used. Respondents suggested that staff should work with a person with AIDS only to the degree they are comfortable doing so.

A major difficulty identified by respondents was non-acceptance of gay lifestyles by staff and family. Staff may not understand what it means to be gay and patients may not be willing to discuss their lifestyle with staff. Many staff were confronted with deep conflicts in their moral values when treating these patients. Limitations in time, training material and expert services are deficiencies when addressing the areas of lifestyle and homophobia. Transmission of the disease is often associated with being gay. It was noted that caregivers' concerns for the public's health may be mistaken for homophobia. Heterophobia in gay patients also posed difficulties in providing care.

Resources which could assist in meeting needs related to lifestyle and homophobia include: content on human sexuality and gay health problems in the curricula of health professionals; establishment of an AIDS society; interdisciplinary education, and public education to dispel myths about the gay lifestyle; an increase in educational materials; media exposure which relays a positive gay image; screening staff who will be assigned to AIDS patients, and outlining explicit expectations for those staff hired; increased resources in chaplaincy, psychiatry, public health and social work to provide integrated, interdisciplinary support services for staff and clients; homosexual chaplaincy services; and sociological research on homosexuality.

2. Drug Subculture

Drug subculture was not identified as an important issue in the programs outside Quebec. Strategies that addressed this issue included education regarding the risks of sharing needles, and referrals to addiction programs. Lack of knowledge related to drug abuse and the drug subculture was identified as a difficulty in care giving. Critical attitudes of staff toward clients in this culture were a deterrent to care. Additional resources required to address needs in this area were: liaison with detoxification, drug abuse and Alcoholics Anonymous staff; and availability of educational material that deals specifically with the drug subculture.

Quebec respondents noted great difficulty in controlling the use of narcotics and psychedelics in the patient's home environment. They also emphasized the importance of establishing connections with this group to prevent the spread of AIDS.

3. Death/Funeral/Spiritual Customs

These issues were not specifically addressed by many programs. Some emphasized a life-oriented versus a death-oriented approach. An individualized approach to client needs was stressed. Some of the strategies used were: memorial services for the gay community; use of chaplaincy services; education for funeral home personnel regarding appropriate precautions with the body; education for family members regarding funeral home policies, options and patients' rights regarding care after death; and education of buddies regarding cultural and religious differences.

A major difficulty surrounding death and funeral arrangements is the potential conflict between the family of origin and the family of attachment. This conflict is particularly evident in the funeral setting. Decisions regarding funeral arrangements (lover versus family) are problematic. Acceptance of the patient's death by the family is difficult. Funeral directors were identified as lacking knowledge regarding options for preparation of the body. Open coffins are an impossibility with persons with AIDS, and certain ethnic groups have traditions that cannot be fulfilled. Palliative care and family follow-up after death are resources which could address some of these concerns.

4. Prostitution

Most programs outside Quebec did not have experience with this issue. Strategies to deal with specific needs of this risk group include: education about informing contacts; distribution of condoms; liaison with representatives from prostitution groups; and using available literature from AIDS support groups regarding prostitution and AIDS. Critical attitudes by staff toward prostitutes is a deterrent to care. Negative attitudes promote isolation in these clients. Educational resources are required to explore health care problems and lifestyle issues related to prostitution. Quebec respondents noted that prostitutes who are infected often continue to be sexually active, and recommended a street worker to gain access to this group.

5. Other

Meeting needs within a cultural context was identified as being important. One strategy to meet the needs of AIDS patients from varying cultural backgrounds was to strengthen alliances between ethnic and cultural groups. Increasing ethnic outreach was identified as being difficult. A suggested resource was creating audio-visual and printed literature on AIDS in different languages.

Summary

The qualitative data provided by respondents gave a rich description of the challenges and problems faced by Canadians who care for persons with AIDS. This data supported the respondents' quantitative ratings of the eight critical issues, but highlighted specific factors that require attention if Canada is to develop effective palliative care services for persons with AIDS. These issues are addressed in the discussion that follows.

Discussion

Results of this survey must be interpreted within the context of the strengths and limitations of the study design. While the survey captured a large part of the Canadian experience in caring for persons with AIDS, it was by no means exhaustive. Rather, the targeted sampling approach was designed to elicit a range of experiences in care and succeeded in doing so. The questionnaire designed by the Working Group evolved

from the professional experiences of its members, several of whom have direct daily contact in caring for persons with AIDS. However, the extent to which the critical issues and subissues identified by the members of the Working Group comprise the entire range of factors influencing palliative care for persons with AIDS is unknown. Although cognizant of these limitations, the Working Group was not aware of any attempts in other countries to capture the perceptions of those involved in the daily challenge of providing care to persons with AIDS.

Importance of Psychological and Interpersonal Support

While palliative care programs have arisen primarily in response to a need for improved symptom management among those dying of cancer, the dominant issue in the care of persons with AIDS is clearly ***not*** one of symptom management. The overwhelming nature of this disease produces profound psychological and interpersonal problems for those affected. Caregivers in a variety of agencies and the friends and family members of people with AIDS are struggling to provide what support they can in the face of limited health care and personal resources. *The primacy of psychological and interpersonal support issues in caring for people with AIDS suggests that any model of palliative care must include funding for personnel resources dedicated to addressing these needs.*

Importance of Infection Control

Findings of this survey suggest there are at least two issues that respondents faced in caring for persons with AIDS: how to gain initial mastery of infection-control techniques; and how to apply them effectively once the volume of patients increased. The presence of diarrhea and skin breakdown present additional problems with respect to infection control.

Location of Death

The fact that very few deaths of persons with AIDS occur at home is not surprising, given the lack of home care resources reported by the respondents to this survey. If such inadequacies persist, use of acute care beds for those who are dying as a result of AIDS will increase dramatically in the future.

Mental Health Risk to the Bereaved

Loss of a loved one from any cause represents a risk to the mental health of the surviving family. However, this risk is compounded in the case of survivors of AIDS-related deaths. The surviving homosexual lover has justified fears for his own survival, and may have already lost important members of his support system as a result of AIDS. Surviving family members are often afraid to discuss their loved one's death due to the stigma attached to AIDS and, as a result, they cannot obtain the support available to other bereaved persons. Respondents emphasized the profound inadequacy of bereavement follow-up services for this population.

Role of Community-Based AIDS Groups

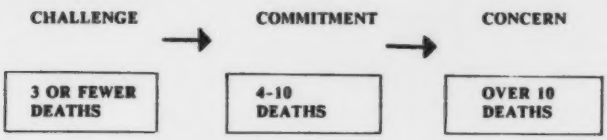
These groups clearly have an extremely important role to play in providing psychological and interpersonal support to persons with AIDS, their families and friends. Their role was emphasized in the qualitative data provided by every type of agency. In addition, community-based AIDS groups were identified as leaders with respect to patient advocacy.

The Effect of Experience

Although there were some differences in the perception of critical issues by type of program, the number of deaths experienced appeared to be the central factor influencing perceptions. Findings suggested the

following model of adjustment to involvement in the care of persons with AIDS (see Figure 12).

Figure 12: Proposed Model of Adjustment to Involvement in the Care of Persons with AIDS



Health personnel and community members who become involved in the care of people with AIDS must first master their own anxiety and learn about the disease if they intend to meet the challenge of providing compassionate care. Once this initial mastery is achieved, a period of commitment to the care of persons with AIDS develops, during which concerns about personal vulnerability decrease. However, as the number of patients affected with the disease grows, these health personnel and community members develop increasing concerns about who is going to provide the care required: will those who have now developed a commitment to compassionate care be abandoned to deal with this problem? The need for an integrated approach to encourage a shared responsibility for care in each community was a solution repeatedly identified by survey respondents.

Conclusions

Canadians who care for persons with AIDS have spoken out about the resources they require to provide effective and humane palliative care in response to this devastating disease. Their recommendations have provided an important source of data in the development of the Working Group's Report. Programs that are currently shouldering the major responsibility for care are stressed and underfunded, and they require immediate assistance to maintain and improve their effectiveness. Other programs need the incentive and support to take on part of the responsibility for care.

This survey has identified several questions for future research. What are the most effective strategies to provide psychological support to persons with AIDS, their families and friends? What are the most effective approaches to reduce the mental health risk for survivors of an AIDS-related death? What is the comparative effectiveness of hospital versus community-based models of care? How can professionals and members of the community at large master their own fears so they can provide compassionate care? These questions and others need to be answered if humane and effective palliative care is to be provided in Canada. Finally, a replication of this survey two years from now may provide useful insights into the changing perception of needs as the AIDS epidemic spreads to all regions of Canada.

Attached to this survey report is a copy of the questionnaire used for the survey.

Instructions for Completing Questionnaire

The information requested in the questionnaire assumes that those completing it have a direct working knowledge of caring for or providing services to people with AIDS. As a result, the questionnaire should be completed by physicians, nurses, administrators or volunteers who have been *directly involved* in planning and/or providing services to people with AIDS.

PLEASE ANSWER THE QUESTIONNAIRE AS COMPLETELY AS POSSIBLE. YOUR RESPONSES WILL BE USED BY THE WORKING GROUP TO FORMULATE A NATIONAL PLAN TO PROVIDE PALLIATIVE CARE FOR AIDS PATIENTS.

The next page requests some demographic information about your program/agency/institution. Please check and fill in the appropriate responses. Also enclosed is a fold-out work sheet. This sheet first asks you to rate the importance of a number of issues in the care of AIDS patients using the following scale:

1 = Not Important
2 = Slightly Important
3 = Moderately Important
4 = Very Important
5 = Extremely Important

Then you are asked to respond to specific questions about the resources you have used to address these issues, the difficulties you have encountered with respect to each issue, and the additional resources you require. Please *print* your responses in the spaces provided. This questionnaire will take a minimum of one hour to complete, and may take longer depending on the amount of discussion among group members completing it.

Please return both the demographic information sheet and the fold-out work sheet in the envelope provided. If you wish to receive a summary of the findings of this study, please contact the National AIDS Centre, Health Protection Building, Tunney's Pasture, Ottawa, Ontario K1A 0L2 after July 1, 1987.

Demographic Information

ID No. _____

Type of program/agency/institution:
_____

Hospital
_____

Palliative care program
a) hospital-based _____
b) community-based _____
c) combined hospital-community _____
d) other _____
Home care/VON/public health _____
AIDS support group _____

Other (please specify) _____

Is this program located in a city/town with a population of:

Less than 30,000 _____
30,000-100,000 _____
100,000-500,000 _____
Greater than 500,000 _____

In what year did you start caring for people with AIDS?
_____

How many AIDS patients have you cared for up to December 31, 1986? _____

3 or under _____
4-10 _____
Over 10 _____

Total accumulated deaths: _____

Can you estimate how many of these patients died at home or in hospital?
Yes _____
No _____

If yes, approximately how many of these deaths occurred:
At home _____
In hospital _____

Core Issues	How Important is this issue in caring for AIDS patients in your program?	What specific strategies/ resources have you used to address these issues in your program?	What difficulties/ deficiencies have you encountered with respect to these issues?	What additional resources (number, types) do you need to address these issues adequately? (please be specific)
Symptom Management Pain	Not Important 1 2 3 4 5 Extremely Important			
Dementia	Not Important 1 2 3 4 5 Extremely Important			
Diarrhea	Not Important 1 2 3 4 5 Extremely Important			
Dyspnea	Not Important 1 2 3 4 5 Extremely Important			
Oral Care (hygiene and pain relief)	Not Important 1 2 3 4 5 Extremely Important			
Loss of Vision	Not Important 1 2 3 4 5 Extremely Important			
Nausea	Not Important 1 2 3 4 5 Extremely Important			
Fatigue	Not Important 1 2 3 4 5 Extremely Important			
Skin breakdown	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			
Psychological Support Loss/grief	Not Important 1 2 3 4 5 Extremely Important			

Core Issues	How Important is this issue in caring for AIDS patients in your program?	What specific strategies/ resources have you used to address these issues in your program?	What difficulties/ deficiencies have you encountered with respect to these issues?	What additional resources (number, types) do you need to address these issues adequately? (please be specific)
Anger/anxiety	Not Important 1 2 3 4 5 Extremely Important			
Guilt	Not Important 1 2 3 4 5 Extremely Important			
Providing affection	Not Important 1 2 3 4 5 Extremely Important			
Fear	Not Important 1 2 3 4 5 Extremely Important			
Loss of self-esteem	Not Important 1 2 3 4 5 Extremely Important			
Depression	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			
Interpersonal Support Relationships with parents and siblings/ other relatives/lovers/friends staff/caregivers	Not Important 1 2 3 4 5 Extremely Important			
Forced loss of anonymity	Not Important 1 2 3 4 5 Extremely Important			
Social isolation	Not Important 1 2 3 4 5 Extremely Important			
Discrimination	Not Important 1 2 3 4 5 Extremely Important			

Core Issues	How Important is this issue in caring for AIDS patients in your program?	What specific strategies/ resources have you used to address these issues in your program?	What difficulties/ deficiencies have you encountered with respect to these issues?	What additional resources (number, types) do you need to address these issues adequately? (please be specific)
Other	Not Important 1 2 3 4 5 Extremely Important			
Independent Living Need for special living accommodations	Not Important 1 2 3 4 5 Extremely Important			
Coordination of care (easy flow between hospital and home)	Not Important 1 2 3 4 5 Extremely Important			
Respite care (relief for caregivers)	Not Important 1 2 3 4 5 Extremely Important			
Home nursing care	Not Important 1 2 3 4 5 Extremely Important			
Home support services	Not Important 1 2 3 4 5 Extremely Important			
Day care	Not Important 1 2 3 4 5 Extremely Important			
Employment	Not Important 1 2 3 4 5 Extremely Important			
Transportation	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			
Legal/Financial Support Income (sources)	Not Important 1 2 3 4 5 Extremely Important			

Core Issues	How Important is this issue in caring for AIDS patients in your program?	What specific strategies/ resources have you used to address these issues in your program?	What difficulties/ deficiencies have you encountered with respect to these issues?	What additional resources (number, types) do you need to address these issues adequately? (please be specific)
Wills (power of durable attorney: public trustee)	Not Important 1 2 3 4 5 Extremely Important			
Funeral arrangements	Not Important 1 2 3 4 5 Extremely Important			
Patients' rights (informed consent, right to confidentiality, patient's role in decision making)	Not Important 1 2 3 4 5 Extremely Important			
Employment	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			
Lifestyle/Cultural/ Ethnic/Religious Considerations related to: Gay lifestyle	Not Important 1 2 3 4 5 Extremely Important			
Homophobia	Not Important 1 2 3 4 5 Extremely Important			
Drug subculture	Not Important 1 2 3 4 5 Extremely Important			
Death/funeral/ spiritual customs	Not Important 1 2 3 4 5 Extremely Important			
Prostitution	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			

Core Issues	How Important is this issue in caring for AIDS patients in your program?	What specific strategies/ resources have you used to address these issues in your program?	What difficulties/ deficiencies have you encountered with respect to these issues?	What additional resources (number, types) do you need to address these issues adequately? (please be specific
Service Delivery Considerations Role of patient with the natural/acquired family in an ongoing plan of care	Not Important 1 2 3 4 5 Extremely Important			
Infection control	Not Important 1 2 3 4 5 Extremely Important			
Staff support	Not Important 1 2 3 4 5 Extremely Important			
Physical facilities	Not Important 1 2 3 4 5 Extremely Important			
Administrative concerns	Not Important 1 2 3 4 5 Extremely Important			
Other	Not Important 1 2 3 4 5 Extremely Important			
Bereavement Support Family residing locally	Not Important 1 2 3 4 5 Extremely Important			
Family residing at a distance	Not Important 1 2 3 4 5 Extremely Important			
Lovers/friends residing locally	Not Important 1 2 3 4 5 Extremely Important			
Lovers/friends residing at a distance	Not Important 1 2 3 4 5 Extremely Important			

Appendix III

Site Visit Report

Introduction

The rapidly increasing incidence of AIDS in the Canadian population poses considerable problems for health and social services agencies as well as individual communities across the country. In October 1985, the Parliamentary Standing Committee on National Health and Welfare undertook a study of the major concerns and problems surrounding the AIDS issue in Canada. Based on testimony from leading experts in the field of AIDS care, the Committee published the *Report on AIDS in Canada* in May 1986. This report contained 23 recommendations for national action on AIDS, of which Recommendations Number 14 and 15 state:

The Standing Committee recommends that, in conjunction with AIDS patients, a group of experts involving the Palliative Care Foundation, economists, hospice operators and public health officials develop a model for integrated palliative care for AIDS patients.

The Standing Committee recommends that a cost-effectiveness analysis be undertaken to examine the model for integrated palliative care as opposed to the present methods of caring for AIDS patients. It is important that the concerns and requirements of AIDS patients and their family and friends be considered in the model.

The Working Group undertook two major activities as part of its work: a Canada-wide survey of people who care for persons with AIDS to determine their perceptions of major issues associated with care, and a series of site visits.

The Working Group decided that much could be learned from a series of site visits to programs with considerable experience in caring for persons with AIDS and their loved ones. Site visits were, therefore, arranged to Montréal, New York City and San Francisco. These cities were selected for site visits both because they had large numbers of persons with AIDS and because they were caring for a range of persons (males, females, children).

This site visit report is part of the Working Group's report on *A Model of Integrated Palliative Care for Persons with AIDS and Their Loved Ones*. Recommendations arising from the site visits are found in the report.

Specifically, the objectives of the site visits were:

- to investigate selective North American AIDS care experiences and evaluate their applicability to Canada's health care system, especially with respect to the network of services for AIDS patients
- to gather information about specific patient groups who will likely be of increasing concern in the Canadian AIDS population
- to investigate specific palliative care services within well-established programs which are not reported in the literature
- to investigate the degree to which existing palliative care programs adapt to the new demand for services by the AIDS group

Various hospitals, hospices, palliative care units, home care programs and community-based AIDS groups were selected in each city to provide information specific to the Working Group's objectives. A list of the sites visited is presented at the end of this report.

A protocol for site visits was developed so findings from each city could be compared. The protocol defined five areas for consideration:

• Shared Responsibility for Care of Persons with AIDS

The Working Group hypothesized that if the responsibility for care of persons with AIDS was shared, better care would result. We believed that persons with AIDS and their families required a variety of services, and that these services could best be delivered by a number of different care providers working in concert.

• Access to Care

The Working Group felt that access to care was critical. Access was necessary to health and psychological support services, as well as financial support services and adequate housing. We looked for how access was established and what factors impeded it.

• Continuity of Care

The Working Group felt that persons with AIDS and their loved ones required continuous, uninterrupted care during the course of their illness. We focused on two types of continuity. The first was continuity within an institution. When institutional care is required, we believe the AIDS patient should receive the appropriate service, delivered by the appropriate person, at the appropriate time, within the scope of the institution's AIDS program. The second was continuity of care within a community which involved the coordination of various provider groups, each of which offered particular services.

• Palliative (Hospice) Care

The Working Group felt it was necessary to explore how palliative (hospice) care was being used by persons with AIDS and how these services were, in turn, adapting to the influx of AIDS patients. The two major questions which we posed were: (1) can palliative care providers shift their thinking to accept that many persons with AIDS will wish to receive very aggressive therapy until death occurs; and (2) can the currently severely limited palliative care resources cope with the large influx of AIDS patients without detrimental effects on their other terminally ill patients.

The need for good pain and symptom management, psychosocial support, spiritual care and bereavement support for family and friends were all seen as requisites for care. Team delivery of care was also seen to be applicable and appropriate for persons with AIDS.

• Moral/Legal/Ethical Issues

The Working Group felt that people with considerable experience in caring for persons with AIDS and their loved ones would be able to confirm the specific moral, legal and ethical issues which emerge and their relative importance to the delivery of care.

AIDS Care in Canada

At the beginning of 1987 when the Working Group began its series of site visits, several cities in Canada were already responding to the needs of persons with AIDS. By and large, care has been given in acute care hospitals. In addition, community-based volunteer associations, primarily arising from the homosexual community, have become strong support and advocacy groups. At the present time, 25 such groups exist across Canada.

Hospital care varies both in quality and quantity. A major problem is educating hospital workers so they are both knowledgeable about and relatively comfortable in responding to the care needs of persons with AIDS. Progress has been made, but more AIDS education is required.

Progress has also been made in caring for persons with AIDS at home, but considerable effort must still be expended if an adequate level of care is to be available.

In British Columbia, 75 percent of the AIDS patients are cared for at St. Paul's Hospital in Vancouver. St. Paul's has an average of 12 to 15 inpatients at any one time, and the hospital has recently opened an AIDS outpatient clinic. St. Paul's works closely with AIDS Vancouver, a strong community volunteer group. AIDS Vancouver has prepared a proposal for a free-standing hospice for persons with AIDS, and the British Columbia Ministry of Health is investigating the feasibility of this proposal.

In Ontario, Toronto is the major centre for the care of persons with AIDS, although other cities around the province also have acquired considerable experience in AIDS care. For Metropolitan Toronto, the Toronto General is the major hospital centre for AIDS treatment. Recently, the Ontario government approved the funding of an AIDS hospice (Casey House) to provide care and sheltered housing for 14 persons with AIDS.

In Montréal, several hospitals share the care of persons with AIDS, with the leading hospitals being the Montréal General, the Royal Victoria and Ste. Justine's. The Royal Victoria has one of the most developed palliative care services in Canada, which includes designated beds for palliative care. AIDS patients have recently been admitted to this unit.

Site Visits

Montréal

Royal Victoria Hospital

The Royal Victoria was the only Montréal hospital officially visited in January 1987. This visit was used as a pilot to develop a protocol for the New York City and San Francisco site visits.

The purpose of this visit was to gather information on the hospital's overall approach to care services for AIDS patients and to assess the role of social workers in the provision of care to persons with AIDS.

AIDS patients were not in a designated unit, but spread throughout the wards. AIDS patients had not been admitted to the palliative care unit at the time of our visit. Aggressive, active treatment continued, unless the patient requested cessation. Home care services were available but very limited.

Social workers acted as case coordinators for persons with AIDS throughout the course of the illness. Community support services were available, but a comprehensive network had not been developed. Housing, alternate residential care, financial assistance (especially for drugs), legal and insurance issues, and discrimination against homosexuals and Haitians were all regarded as problematic.

Inservice training about AIDS was ongoing for all staff, including custodial, kitchen and laundry staff.

Summary of Montréal Visit

In Montréal, care for persons with AIDS is primarily a hospital-based system supplemented by a newly emerging community service network. Persons with AIDS had access to services through provincial health insurance; however, outpatient drug and nutritional supplement costs were not funded by the province of Quebec. Therefore, some Montréal hospitals were subsidizing these costs. This burden creates an increased strain on hospital budgets which can only be eased by the availability of additional resources.

To meet the psychosocial needs of persons with AIDS and their families, social workers in Montréal are having to "forge new ground" to be both educators and service innovators. All members of the care team were confronted with issues from this new patient group, issues not usually within their service expertise.

In Montréal, we learned of the concerns of a major palliative care service that its limited resources would be overwhelmed if it took a major role in caring for AIDS patients.

New York City

A. Specific Visits

1. Sloan-Kettering Cancer Clinic (Manhattan)

This hospital serves primarily homosexuals who have AIDS or who are HIV-positive, and secondarily persons who have contracted the disease through drug use. Because it is a private hospital, the patients are physician-referred and have average annual incomes of $35,000.

Although the Social Work Department takes major responsibility for AIDS patients and the coordination of their care, only a few social workers are presently assigned to the AIDS team. Hospital policy states that AIDS patients must have private rooms and be in isolation. Patients make the decisions about being part of research projects and on the extent of active treatment (for example, resuscitation). Support for staff is built into the weekly meetings of both the AIDS team and the staff on each floor.

2. Montefiore Hospital (Bronx)

This hospital serves primarily persons who have contracted AIDS through drug use and serves a large percentage of Blacks and Hispanics. The hospital is affiliated with North Central Bronx Municipal Hospital, Albert Einstein Medical Center and Beth Abraham Hospice.

There are no designated AIDS units, so AIDS patients are presently distributed throughout the hospital. There is no official AIDS team, and all hospital physicians are expected to provide care. Application has been made for funding as an AIDS centre through new government programs.

Patients at the Montefiore preferred to die in the hospital because they were assured of medical services and their housing was inadequate for home care. Patients made the decision about the extent of active treatment.

Social workers carried large caseloads and followed patients on both an inpatient and outpatient basis. An inhouse home care team of nurses and homemakers provided services at home to AIDS patients. The Volunteer Department is developing a corps of volunteers from the drug abuse program to assist AIDS patients. The Social Work Department provides group services for patients, a family and relative support group, an HIV-positive group and a bereavement group.

There is no formal staff support program at the hospital.

3. Albert Einstein Medical Center (Bronx)

This hospital serves primarily Blacks and Hispanics, and is well known for its services for children with AIDS.

Children with AIDS live from seven to eight years, but are developmentally delayed by approximately two years. The diagnosis process is difficult, since a lung biopsy is necessary to confirm the diagnosis. This procedure is often delayed due to the danger of infection and pain for the child.

The hospital operates a clinic one day a week for testing all family members; a day-stay program for medical treatment of children; and an inpatient service. A day care program operates at the Bronx Municipal Hospital Center.

Housing is a critical need for the families of children with AIDS. Abandonment of children is not a common problem, however, since social workers identify

extended family members, such as aunts and grandmothers, at the time of diagnosis and ensure that care is maintained through this extended family or a foster family. Children with AIDS usually die in hospital, and bereavement follow-up is done by a social worker.

The Social Work Department has limited staff, and the hospital has no formal support mechanisms for staff.

4. Bronx Municipal Hospital Center

This municipal hospital serves primarily persons who have contracted AIDS through drug use; thus, patients usually have a low socioeconomic status and chronic housing problems. Six percent of inpatients have AIDS-related illnesses. AIDS patients are distributed throughout the hospital, but this situation may change when new funding becomes available through the AIDS center designation program from the state of New York. Concern was expressed regarding the difficulties of attracting dedicated staff to work only on an AIDS unit.

The day hospital program operates on private foundation money. The hospital intends to provide high tech care in homes (primary care model on an outpatient basis) which will include the designation of primary care physicians as case managers for AIDS patients on both an inpatient and outpatient basis.

The hospital has a multidisciplinary AIDS team. Two social workers are assigned to the team and act as consultants to the physicians and nurses. The cases in which they provide consultation are not necessarily part of their caseload.

The hospital perceives the care of AIDS patients as the entire institution's responsibility, not just that of the AIDS team. Ongoing staff education is considered important, and AIDS education has been incorporated into the orientation program for nurses. Other staff support is informal.

5. Beth Abraham Hospital: Ritters-Scheuer Hospice (Bronx)

The hospice is a 16-bed facility for terminally ill patients. Ten percent of inpatients are AIDS patients. The average stay for an AIDS patient is 30 days. The hospice receives approximately 15 referrals per week and has 10 AIDS patients in its home care program.

Criteria for admission to the hospice program include a diagnosis of a terminal illness with a life expectancy of less than six months and the rapid onset of dementia.

Staff ratios for the inpatients are one-to-three on the day and evening shifts, and one-to-four on nights. Average length of a home visit by the nursing staff is 1.5 hours. The hospice has single and double rooms, but isolation procedures have caused difficulties.

To qualify for hospice funding under the U.S. hospice legislation of 1983, 80 percent of patient care must take place at home and 20 percent in hospital. These guidelines are very difficult to achieve with AIDS patients, particularly with those patients who also must deal with New York City's housing problem.

The hospice is assisted by the AIDS team from Montefiore Hospital. The AIDS team meets weekly and consists of a physician, a physician assistant, a nursing supervisor (registered nurse specialist) and a social worker. The inservice training program is mandatory for all staff.

The Hospice has a home care focus and provides an extensive home care service. It also offers a formal bereavement program that is staffed primarily by volunteers because no government funding is provided for such programs. The bereavement program includes telephone follow-up, memorial services and luncheons.

6. St. Vincent's Hospital Hospice Program (Lower Manhattan)

St. Vincent's is a fairly well-established hospice (palliative care) program that has been able to adjust reasonably well to the increased volume of AIDS patients. It is important to note that St. Vincent's Hospice Program did not seek medicare certification and therefore is not subject to the many restrictions imposed on certified hospices. For example, it does not restrict itself to the terminal AIDS patient, but provides care for the newly diagnosed patient as well as those who have poor support systems. It should be noted that the hospice continues to care for non-AIDS patients, and priorities among patients' needs are determined when hospice staff are assigned.

The Hospice Program serves both inpatients who are cared for throughout the hospital, and those who are out-patients connected to relevant hospital clinics. The hospice team provides consulting, coordinating and counselling services rather than direct patient care. Direct care is given by ward staff in the hospital or by home care service staff in the community. Social workers play a major role in the services delivered.

The thrust of the Hospice Program is to keep AIDS patients at home, and they believe some success is being achieved. The program operates on the belief that most AIDS patients can be maintained at home; they do not need constant nursing care, but they do need careful supervision. Such supervision is usually accomplished through weekly assessments by hospice nurses, and careful and constant contact with the home health aides who provide the care.

Bereavement care is a major aspect of the Hospice Program. The Gay Men's Health Crisis Center refers persons to the bereavement support groups run by the program. The public health value of these groups appears to be recognized by all providers in Lower Manhattan.

The hospice has been the initiator of a mandatory and continuing staff education program about AIDS at St. Vincent's. All staff at the hospital must participate, from physicians to administrative staff, from porters to students.

B. Summary of New York Visit

In New York City, the care of persons with AIDS and their loved ones is perceived to be primarily a hospital responsibility. Hospitals are seen as the organizers of care, whether that care is delivered in a hospital bed or in the community.

New York City accounts for almost one third of all AIDS cases in the United States. Despite the highest incidence of AIDS in the world and many years of experience with the disease, New York City is only just beginning to develop a regional system of care through the creation of state-funded regional referral areas.

Due to the high incidence of AIDS among women and children in New York City, a special effort has been made to involve extended family members in the delivery of care to these groups and, as much as possible, care is given in the home setting. Home care is not always practical, however, because New York City's general housing crisis and the socioeconomic status of many Blacks and Hispanics often means that the patient's home is not considered safe or adequate for home care. Also, as hospitals are the organizers of care, provision of home care has placed an additional burden on already overtaxed hospital personnel who must then provide care in both settings.

Entry into the health care system is problematic in New York City, since the system does not provide for universal access. Financial costs of care are very high, both for the individual and for the institution providing the care.

In New York City, attempts are being made to ensure that continuity of care is provided to persons with AIDS whether they are in the hospital or using available community services. Relatively new types of health care providers, such as nurse practitioners, physician assistants and home attendants, are being employed to achieve improved continuity of care. The Gay Men's Health Crisis Center Inc. has developed an effective network of services and educational programs. As well, the Crisis Center is reaching out to persons with AIDS from other lifestyle, cultural and socioeconomic groups.

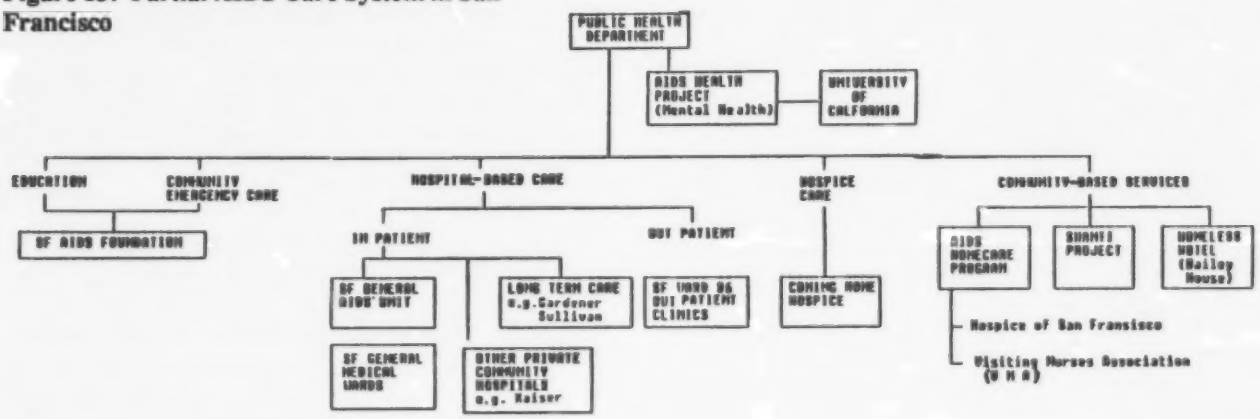
In the sites visited, social work departments were attempting valiantly to meet the overwhelming needs of this new patient group and their families, but their resources were stretched very thinly. Also, the need for inservice training and support groups for hospital staff was emphasized repeatedly.

San Francisco

A. Specific Visits

Figure 13 illustrates the overall system of care for persons with AIDS and their loved ones in San Francisco.

Figure 13: Partial AIDS Care System in San Francisco



1. San Francisco Department of Health

The San Francisco Department of Health was appointed by the city of San Francisco to be the coordinator of AIDS care in the San Francisco area. As well, it receives the available city and state funds and, in turn, channels them to the various AIDS programs. For our purposes, it was interesting to note that a coordinator of care was appointed early in the establishment of the network of AIDS care services and that the city's Department of Health was seen to be the appropriate body to carry out this role.

2. San Francisco AIDS Foundation

The AIDS Foundation had its beginnings in the Department of Health, but now exists as a privately incorporated, non-profit organization. Its mandate is twofold: to oversee educational activities in the city which includes preparation of educational materials and to provide community emergency care for persons with AIDS. It has a paid staff of 52 persons and a volunteer staff of 400. It receives its funding from the city, the state (includes federal monies channelled through the state) and private donations.

The Foundation provides educational material in various forms (written material, films) to the general population as well as to specifically targeted groups.

It provides emergency housing for up to eight persons at one time and operates a food bank used by approximately 200 persons a month.

It also provides a 24-hour, seven-day-a-week hotline staffed by its 400 volunteers. As it is the only one of its kind in the state, the hotline presently serves all California. The Working Group was interested in how this type of community support service operated as well as how it fit into the network of services in the community. Clearly, it was performing necessary and valuable functions and appeared to be well connected to the network of care. Concern was expressed by the Foundation about how long it could continue to expand its services to meet the increasing demands of new groups in the AIDS population.

3. San Francisco General Hospital

The San Francisco General Hospital is the pivotal point for AIDS services in the San Francisco area. As the city and county hospital for the area, it is the major site of outpatient and inpatient services.

Inpatient services comprise a 20-bed AIDS unit, psychiatric beds and beds as required on other medical units. The AIDS unit has a patient-to-staff ratio of 4:1. It has one full-time attending physician with a medical support team of seven part-time physicians. In addition, a medical social worker and counsellors from the Shanti Project care for psychosocial needs of patients. Patients are accommodated in private rooms, but the hospital anticipates shared rooms in future since they have insufficient beds. Private rooms are currently preferred to ensure patient privacy rather than for reasons of infection control.

San Francisco has about 120 diagnosed cases of AIDS per month. About one third of these patients come to the inpatient unit. Approximately 70 percent of those discharged go home or to an extended care facility; the remainder are discharged due to death.

Approximately 15 patients at any one time are located in other medical units of the hospital in single rooms, either because of special treatment they are receiving or because there are no beds available on the unit.

Approximately one AIDS patient a month will be sent to the psychiatric unit, usually for neuropsychological testing.

Ward 86 of the San Francisco General houses the AIDS/oncology outpatient clinics. Staff of the clinic is composed of four oncologists, a medical social worker, eight Shanti counsellors, one psychologist and 3.3 nurse practitioners. Clinics are held five half-days a week for persons with AIDS, and there are 800 clinic visits a month.

As Ward 86 serves as a centre for coordination of care, most services in the San Francisco area are accessible through the clinic, including many of the social and welfare services.

Because of the volume of patients cared for in the unit and in outpatient clinics, especially the latter, there is an acknowledged need for specially trained staff and considerable staff support. Staff also noted such problems as lack of standards of care; presence of complex ethical issues, especially around the use of highly experimental drugs, and having to deal constantly with young, dying persons with extremely short life expectancies.

4. Long-Term Care Services

We were told repeatedly during our site visit that it was critical to the San Francisco network of AIDS care that

more long-term care facilities be made available for persons with AIDS whose condition did not require inpatient, acute care beds, but who could not be sufficiently cared for in the community. Only one facility, Gardener Sullivan, provided such beds, and the number of beds available was not sufficient to meet the need.

5. Coming Home Hospice

Coming Home Hospice is a new component of the services offered to persons with AIDS. This converted Catholic convent provides 15 beds for terminal care, with five to 10 being used for persons with AIDS. The hospice is not considered to be a skilled nursing facility, although a licensed vocational nurse provides eight hours of team leadership a week and monitors medications. In addition, other community home care nurses visit daily to supervise care. A social worker visits periodically, and there is a resident cook. Attendant care is available for approximately 15 to 20 hours a week. All other care is delivered by volunteers.

Criteria for admission include: a diagnosis of a terminal illness with a life expectancy of less than six months; conditions which make it impossible for the patient to remain at home; no need for ongoing and constant nursing care, and no use of intravenous equipment. Patients may book a place for respite care if beds are available. The charge of Coming Home Hospice is $30 a day.

6. AIDS Home Care Program

Home care services for persons with AIDS were created when two provider groups merged in 1983 and began a combined group to receive funding from the San Francisco AIDS Foundation. The two groups were the Visiting Nurse Association of the Pacific Presbyterian Medical Center and the Hospice of San Francisco. The service has cared for 600 AIDS patients to date. Thirty-five percent of patients die at home. Fifty percent of all AIDS patients in the San Francisco area get home care at some point during their illness.

The home care staff is composed of a nurse who is on 24-hour call; social workers who do assessments and make weekly visits to the patient; medical consultants, attendants and volunteers. Patients on home care may receive a maximum of eight hours a day of attendant care. Eighty percent of patients receive the maximum care available. Volunteers for the home care program are from the Shanti project.

7. Shanti Project

The Shanti Project began in 1974 as a community support program for persons suffering from terminal illness. In 1981, after experiencing a severe financial crisis, Shanti became a new organization dedicated specifically to care of persons with AIDS. In 1982, it began to receive about 40 percent of its $2.4 million annual budget from the city of San Francisco. Thus far, Shanti has provided assistance to 2,200 gay men with AIDS. Eighty percent of persons with AIDS in the San Francisco area receive services through the Shanti Project. It provides services to those with a confirmed diagnosis of AIDS and to those with AIDS Related Complex if they are extremely ill.

Shanti has approximately 450 volunteers. Three hundred work as emotional support volunteers; the other 150 provide practical support. Emotional support volunteers receive 44 hours of training. They work on a one-to-one buddy system with persons with AIDS.

In addition to the emotional and practical support volunteer programs, Shanti also has a residence program. Shanti leases 12 houses in the San Francisco area which can accommodate 47 persons at any one time. Most of the persons using Shanti accommodation are gay men (84 percent) and are able to care for themselves upon entry into the residence program. As their

conditions deteriorate, the residents receive appropriate assistance from a variety of care groups.

Houses leased by Shanti are maintained by two maintenance specialists. Weekly resident meetings are held to ensure problems which arise are dealt with quickly. Shanti staff noted the difficulty they had mixing different groups of persons with AIDS in their residence program.

Shanti provides approximately three full-time counsellors to the inpatient unit and one full-time counsellor to the outpatient clinics at the San Francisco General Hospital.

Shanti has a support program for families, friends and lovers of persons with AIDS prior to death, and bereavement groups after death has occurred.

Shanti also has a recreation program for its residents.

During our site visit, we were told that care for the caregiver was insufficient in its program and that this problem would need attention in future. Caregivers, especially those in the gay population, are becoming exhausted as more and more demands are made on them.

8. Homeless Hotel (Bailey House)

The Homeless Hotel is a 44-bed facility used primarily for homeless intravenous drug users who have AIDS or AIDS Related Complex. The hotel was spearheaded by three social workers who perceived the need for such a facility three years ago. The hotel opened in 1987 and is run by Catholic Family Services with funding from the city Health Department.

Residents are provided with a room, meals, maid service and laundry service. They are required to pay for these services with a portion of their welfare monies. A money manager at the hotel supervises the disposition of residents' welfare cheques to ensure payment for room and board is made to the hotel. It is believed by those involved that more or expanded services such as the Homeless Hotel will be needed as the drug user population with AIDS becomes larger.

B. Summary of San Francisco Visit

San Francisco's care system for persons with AIDS and their families was the most highly developed system encountered by the Working Group. Among the reasons were the sheer size of its AIDS population; the large and powerful lobby group within the city's gay community; the early support given by the political hierarchy of the city and the state; and an early recognition among the various provider groups that there would be little chance of preventing a full-scale crisis unless they worked together.

The network of services in San Francisco includes education, community emergency care, both inpatient and outpatient hospital care, hospice (palliative) care, and professional and volunteer community-based services. It should be noted that the services of volunteer groups are critical to the network of care in San Francisco.

Care in the home is a central feature of San Francisco's network of services, both for quality of care reasons and to minimize the costs of care. It is delivered by a variety of professional and volunteer groups.

The primary entry point into the network of services is through outpatient clinics of the San Francisco General Hospital (a city and county hospital), although a person can gain access to the entire care system from any level and through any provider. Outpatient clinics serve as a coordination centre where representatives of most care provider groups are either physically located or available at scheduled times during clinic hours.

A 20-bed inpatient unit is also located at the San Francisco General Hospital. Demands on this unit are increasing rapidly, and thought is now being given to establishing a greater number of long-term care beds elsewhere in the city to support the inpatient unit. Additional beds would not only help to ease the burden on the unit, but also would permit care to be delivered in more appropriate locations for some patients. It is also anticipated the present private rooms on the unit will be converted to double rooms to accommodate the increased number of patients.

Additional innovative community-based services exist in the area. The AIDS Foundation of San Francisco provides emergency housing and a food bank for persons with AIDS. As well, it operates -- entirely with volunteer manpower -- a hotline for AIDS for the state of California. The Shanti Project is an impressive volunteer service which provides practical assistance and psychosocial support for people who are able to remain at home. Home care services are also available through the Visiting Nurses Association of the Hospice of San Francisco. A newly formed hospice program has a small number of beds as well as home support services.

The possibility of continuing care throughout the illness in appropriate locations and delivered by appropriate persons appeared to be good in San Francisco. There was an excellent range of services and good, if somewhat informal, mechanisms for cooperation among the provider groups to service individual patients and their loved ones.

The establishment of this impressive network of services for persons with AIDS and their families and friends did have, we were told, negative repercussions for a time on care of persons suffering from other terminal diseases, especially cancer. While this situation appears to have been rectified, it did create serious problems both in hospital and community-based services.

Summary of Findings of Site Visits

The results of our site visits have been organized into six sections which we believe are key areas of consideration to develop a system of palliative care for persons with AIDS and their families and friends.

A. Care for Persons with AIDS and Their Families and Friends

Our research led us to conclude that a wide range of services, provided by a variety of health care professionals and others, were necessary for quality care of persons with AIDS and their loved ones. It also led us to conclude that such care was best delivered by a well-coordinated team of individuals comprising both professionals and volunteers.

The survey helped us to describe the variety of services required. Our research also helped us to understand the need for these services may be different during the various stages of illness, from diagnosis to death. It was quite apparent from both our survey and site visits that psychological and social support are of paramount importance throughout the illness, but most particularly during the terminal stage when death is near.

Both the site visits and the survey clearly indicated that mental deterioration is an important consequence of AIDS. The latest statistics indicate that some form of mental deterioration, ranging from mild and stable to severe and rapidly changing, is present in approximately 60 percent or more of persons with AIDS. Mental deterioration is a major problem during the terminal stage of the illness and creates specific care needs and may even result in the need for special facilities. Because mental deterioration may occur at any point in the disease, there is a need for persons with AIDS to settle their affairs early while able to do so. Such things as making a will must be done at an appropriate time, and assistance may be a necessary service.

B. Care Delivery

Our research showed the person with AIDS, the caregivers and the family should jointly share the decision as to the type and location of care. We also learned that the availability of different care options is important. For example, it is highly desirable for persons with AIDS who wish to remain in their homes to do so. During the site visits, we discovered many innovative approaches to providing care in the home, and it is clear that quality care for persons with AIDS can be provided in the home, if there is the will and determination and the resources.

The importance of care in the home does not, we learned, diminish the importance of high quality institutional care when required. Repeatedly, we heard of the need to plan institutional services carefully, not after crisis has struck. Repeatedly, we heard of the need to train staff properly and to provide patients with both caregivers and environments sensitive to the needs of persons with AIDS and their loved ones.

What is needed is a carefully integrated network of care composed of both community-based and institutional services. If persons with AIDS and their loved ones are to receive high quality care, then they must be able to receive what they require, when they require it, in the most appropriate location. Needless to say, such a network does not magically fall into place. Rather, it takes considerable thought, planning, cooperation and hard work to achieve.

Persons with AIDS certainly require medical services, but our research indicates that there is also an equal and, in some instances, a greater need for what are usually thought of as social services. We learned that it was necessary to achieve a balance between the medical and social dimensions of care. We were told many times that this need is frequently an issue when funding allocations are made, that is, social dimensions are generally funded poorly. Failure to provide adequate social service support affects not only the person with AIDS, but the caregivers as well. Where social services are lacking, medical and nursing staff often attempt to provide social service support in addition to their other caregiving responsibilities, resulting in staff "burn-out."

In addition to loved ones, caregivers of persons with AIDS may also include other professionals and volunteers. Many examples of strong, well-organized community volunteer groups exist, and their contribution to the delivery of care is well documented. Both professionals and volunteers have appropriate roles to play, and a strong care team can emerge if their roles are clearly identified and if they work together.

The feasibility of mixing AIDS patients within an institutional setting is another issue which emerged during the site visits. There is no clear consensus on the issue of mixing the AIDS patients either within the AIDS patient group itself or with other patients. What appears certain is that the volume of patients will most certainly influence any decision with regard to aggregating or integrating AIDS patients within the general hospital population to minimize the stigma presently associated with this disease.

A final care delivery issue which emerged from our site visits was the repercussions of AIDS on care available to persons suffering from other terminal diseases. We were given examples in the United States of how care for terminal cancer patients suffered when the number of terminal AIDS patients reached significantly large numbers.

C. Education

For the purposes of this report, three specific education issues for caregivers are relevant. The first is the education of caregivers about the course of the disease as well as the types of care required at various stages in

the illness. The second issue is the education of caregivers as to how they can protect themselves from getting AIDS--specifically, teaching infection-control techniques which are both adequate for protection and humane as possible for the person with AIDS. Both these education needs involve the acquisition of technical skills and the recognition of the natural fears which arise for caregivers when dealing with AIDS. Both are necessary to ensure quality care throughout an individual's entire illness, but are of utmost importance in the terminal stage when contact with the person with AIDS is at a maximum and when the need for care is most demanding.

The third education issue for caregivers -- and the most difficult to achieve -- involves understanding the lifestyle and values of persons with AIDS and their loved ones. Without such an insight, the care provided may be technically superb but incomplete. Such a lack of understanding may also lead to forms of discrimination which, in turn, results in physical and emotional hardship for those with AIDS and their loved ones.

D. Support for the Caregivers

Our site visits confirmed that the psychosocial needs of the caregivers must also be considered. Support programs are needed for both professional and volunteer caregivers, which allow for the ventilation of the complex range of feelings surrounding the demanding task of caring for young, terminally ill persons with AIDS.

E. Policy

Repeatedly, during our site visits, we heard of the need for policies, especially government policy, which would provide a basis on which care for persons with AIDS and their loved ones could be developed.

In practical terms, we learned that effective networks of care for persons with AIDS and their families emerged when governments at various levels first made a commitment in policy to create these networks and then backed up these commitments with funding allocations. We also saw the reverse, where lack of commitment impeded the establishment of adequate networks of care. We learned as well that policy regarding research, education, prevention and testing appeared to be of top priority, with policy for the care of persons with AIDS and their families, especially in the terminal stage of illness, falling behind. We must question whether or not this minimal emphasis on care is appropriate.

F. Economics

The economic issues associated with AIDS are many, varied and largely unexplored. For our purposes, the economic issues were divided into two broad categories: those concerned with the individual with AIDS, and those concerned with the costs to the health and social service system.

For the person with AIDS, there is generally a sharp decline in economic status, since the illness frequently leads to loss of employment and income. In turn, unemployment may result in draining all savings and assets. The person with AIDS may be forced to depend on loved ones or the welfare system for support. A productive, contributing member of society may be reduced to a completely dependent existence. The effect on the individual is, of course, devastating; however, there is also a significant cost to society. The nature and magnitude of this cost, however, has yet to be examined.

The second economic issue is the cost of caring for persons with AIDS within the health care system. Our health care system is already overextended, and AIDS will add a considerable strain on the system. The impact of AIDS will be felt particularly by the currently undeveloped and underfunded palliative care system.

The high cost of drugs for persons with AIDS has emerged as an issue, but there are many more serious cost issues yet to be explored. For example, we have no reliable cost data that tell us about the overall costs of caring for a person with AIDS during the entire episode of illness. Current United States estimates indicate that the cost for caring for persons with AIDS during their entire illness is between $40,000 and $50,000. While these figures are often quoted, they are difficult to substantiate. Similarly, there are little cost data regarding the difference in the cost of caring for a person at home versus an institution. Nor do we know just how much care can be delivered at home and at what cost.

We do know from our survey that expensive institutional care is now being used because there is no alternative service, not because the person requires or prefers institutional care. We also know from our survey and site visits that expensive hospital care is now being used when less intensive and less expensive institutional care, such as nursing home care, would be more appropriate.

Of particular relevance to the terminal stage of illness is the fact that many persons with AIDS would prefer to die at home, but the necessary services are not available. Needless to say, these dying persons also occupy expensive hospital beds because no other alternatives are available.

We concluded from our site visits and survey that the study of many of these cost issues must begin now so that, as the number of AIDS cases increases, the allocation of our scarce health care resources will be efficient, effective and will result in quality care to persons with AIDS and their loved ones.

G. List of Specific Sites Visited

1. Montréal

Royal Victoria Hospital

2. New York City

Sloan Kettering Cancer Clinic
Montefiore Hospital
Albert Einstein Medical Center
Bronx Municipal Hospital Center
Beth Abraham Hospital: Ritters-Scheuer Hospice
St. Vincent's Hospital Hospice Program
New York City Social Service Department

3. San Francisco

San Francisco Department of Health
San Francisco AIDS Foundation
San Francisco General Hospital
Coming Home Hospice
AIDS Home Care Program
Shanti Project
Homeless Hotel (Bailey House)

Appendix IV

Aids Disease Trajectory

For the purposes of this report, the disease trajectory for AIDS will begin with diagnosis. Once a patient has been given a diagnosis, the question arises: what will happen?

Manifestations of AIDS

AIDS frequently presents in four major ways:

1. Pneumocystis carinii Pneumonia (PCP)

PCP presently occurs in approximately 50 percent (50%) of the total AIDS cases in Canada. This protozoan mainly affects the lungs in the form of a pneumonia. The first episode may be so severe that despite intensive treatment the person dies. Patients may experience several episodes of PCP before death occurs. Between episodes, the patient may be relatively well and active.

2. Kaposi's Sarcoma (KS)

Approximately 20 percent (20%) of AIDS patients developed KS. This tumor affects the skin and other internal organs. Patients with KS usually remain well and active for a more prolonged period of time.

3. PCP and KS

About nine percent (9%) of patients have both problems. As expected, the prognosis is shorter than with KS alone. The quality of life and the activity level of the patient varies considerably from one individual to another.

4. Other Opportunistic Infections (OI)

Twenty percent (20%) of cases develop a variety of uncommon infections. Some of these are listed in Table 7 of this appendix. The activity level of the patient is quite variable, depending upon which infection occurs and its severity.

These categories of AIDS progression are shown in Figure 14 at the end of this appendix.

Stages of Disease

As discussed in section 3.2.1 (page 28) of the report, the Working Group has identified the stages of AIDS as: Early Stage, Progressive Stage, Advanced Stage and Terminal Stage. Although somewhat arbitrary, these stages have relevance to decisions about the intent of care.

Progressive Problems

AIDS patients encounter many complications and problems. For the purposes of this report, they may be grouped into three general categories: immune system problems, treatment complications and psychosocial problems. These categories reflect some of the serious implications of AIDS.

HIV causes the body's main defence mechanisms to falter. The patient's immune system is severely weakened, thereby allowing a wide variety of common and uncommon infections to occur. The effects in terms of symptoms are diverse, debilitating and disheartening. Available drugs have serious side effects. At times, the treatment complications may be worse than the effects of the disease itself; quality of life as well as length of life issues require informed decisions by the patient in conjunction with the family and care staff.

The third area of problems, the psychosocial impact of AIDS on the patient and loved ones, is also important, particularly in terms of the personal stress and its impact on decision making. High anxiety, neurological and mental impairment, serious depression or fear

jeopardizes accurate insight, with possible later regrets. Families, friends and caregivers are similarly affected by this situation.

1. Immune System Problems

The immune system is essential to life as the main mechanism for fighting a host of potential infections. As seen from Table 7, these infections create very disabling and life-threatening times for AIDS patients. Most of these infections are quite rare in a person with an intact immune system. Table 7 is not an all-inclusive list, but serves to illustrate some of the difficulties encountered in AIDS care. It should be noted that the sites listed are ones which most commonly occur; however, with further symptoms, other sites may also become involved.

Table 7: Infections and Tumors Associated with AIDS

Categories	Site	Symptom Examples
A. Infections		
i) Protozoal		
Pneumocystis carinii Pneumonia	Lungs	Cough, fever, sweats, shortness of breath
Toxoplasma gondii	Brain	Fever, headache, seizures, confusion, behavioural changes, dementia, unconsciousness
Cryptosporidium	Intestinal Tract	Profuse watery diarrhea, dehydration, debility, malnutrition
ii) Fungal		
Candida albicans	Mouth Esophagus	Dysphagia, substernal pain, malnutrition
Cryptococcus	Brain (and other)	Fever, headache, seizures, confusion, dementia, unconsciousness
iii) Viral		
Cytomegalovirus	Eyes Brain	Retinitis, blindness Fever, headache, seizures, confusion, behavioural changes, dementia, unconsciousness
Human Immuno-deficiency Virus (HIV)	Brain*	Behavioural changes leading to stable or rapidly progressive dementia
iv) Bacterial		
Mycobacterium avium-intracellulare	Lungs, liver, Bone Marrow Lymph Nodes	Fever, night sweats, Lymphadenopathy, productive cough
*Infection of the brain is frequently seen in children.		
B. Malignancies		
Kaposi's Sarcoma	Skin lesions and other organs	Loss of body image, disfigurement, malnutrition, pain, obstruction, fever

Lymphomas	Brain	Fever, headache, seizures, behavioural changes, dementia, unconsciousness

2. Treatment Complications

Some of the drugs used for treatment of infections have adverse side effects. At times, these effects may be more severe than the disease itself; therefore, prudence is needed in decisions about continuing aggressive treatment, especially where the benefit of the drugs is questionable. These side effects may include:

anemia
anorexia
bone marrow depression
diarrhea
dizziness
drowsiness
fatigue
fever
hair loss
hyperglycemia
hypoglycemia
hypotension
irritation
itching
liver dysfunction
myalgia
nausea
neutropenia
psychosis
renal dysfunction
skin discolouration
skin rash
vomiting
weakness

3. Psychosocial Problems

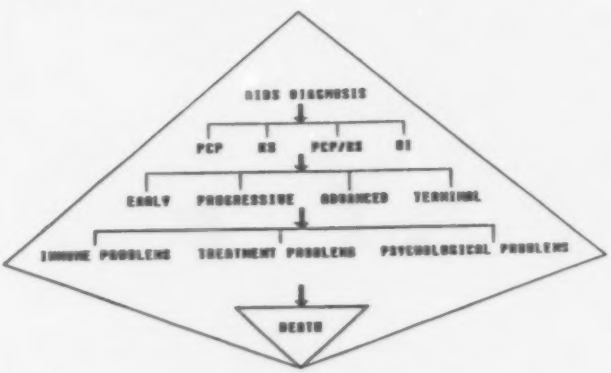
This area has many issues. As the disease progresses, some of these factors also change in intensity. Where there has been good exploration and intervention early in the disease and ongoing support, the patient and family suffer less stress. Some of the issues are:

anger
depression
fear
grief
loss of benefits
loss of employment
loss of housing
loss of self-worth
loss of support from friends and loved ones
poverty
social isolation
spiritual crises/exploration
suicidal ideation

Final Outcome

At present, the outcome of AIDS is uniformly fatal with time. The overall disease trajectory is shown in Figure 14.

Figure 14: Disease Trajectory



Appendix V

Location of AIDS Care

Most patients affected by any disease desire to be as independent as possible throughout the course of their illness. Most also prefer the comforts of home as compared to hospital accommodation. AIDS patients have the same desires. Health care institutions and governments are also in agreement. The question then is: how can AIDS patients be cared for at "home" and what is required?

First, it is necessary to define the two parts of a "home." A home has a **quantitative** nature with such characteristics as a location of residence, street address or physical structure. However, a home generally means much more than simply quantity. A home also has a **qualitative** nature -- a place to go to relax, to get away, to find nurture, to be with loved ones and friends. This aspect becomes very important for patients who are unable to be cared for in their physical homes and must spend their remaining days in an institutional setting. One of the valued aspects of palliative care units, which unfortunately are rare in Canada, is the attempt to create an "atmosphere of home" on the ward. This "home-setting" involves physical changes, such as allowing people to bring in pictures, and restructuring some rooms for visiting and for overnight stays by loved ones. Creating a home-like atmosphere also involves modifying routines to accommodate patients and family needs, such as open visiting hours, allowing family pets and creating flexible hours for physical care during bath time, snack time and bedtime. Therefore, wherever the actual location of care, much attention should be devoted to providing "home." These changes, of course, should be independent of any particular disease diagnosis such as AIDS.

In assessing the physical location of care for persons with AIDS, the bi-fold nature of home must be always kept in mind. There are perhaps many ways in which AIDS patients may be cared for in their physical home by using support services already available and creating new ones for specific circumstances. There are, for example, a variety of nursing services, homemaking services, occupational and physiotherapy services. Some areas have laboratory services which come to the home. More recently, high tech services formally available only in hospitals are now more common in a home setting, including such things as continuous oxygen equipment, forms of kidney dialysis, and IV and TPN therapy. When considering needs of AIDS patients, communities must be aware of already existing services in their community as well as potential new services. Some provinces have very innovative mechanisms for developing home supports as extensions of hospitals; New Brunswick's extramural hospital program is an example. Other forms of outpatient programs like day-hospitals or clinics serve valuable roles in supporting care at home.

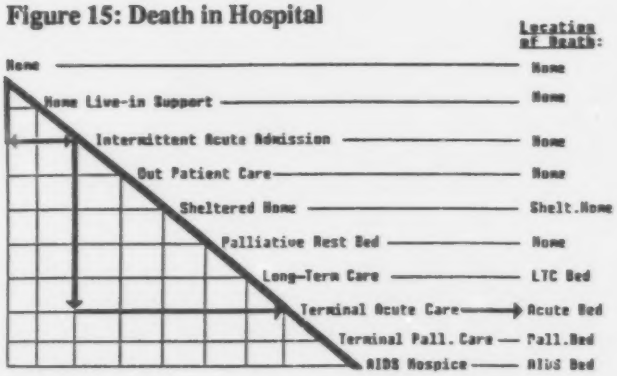
The conclusion of the Working Group is that there is no one best model of care at home for AIDS patients, but rather the best model would be a potential matrix of interaction and coordination among systems, both those already in existence and those which could be developed to meet the needs of a particular community. The need for closer interaction between home programs and hospital programs cannot be overemphasized. At times, part of the obstacle is the present separation of funding established by some provinces. Until such time as budgets are developed to reflect closer interaction between home and hospital, there will be some limitations.

The Working Group was very interested in the different kinds of AIDS care approaches it observed in the United States. The Shanti residence program stands out as an example of a sheltered home concept. Also, a variety of live-in supports provided full travel expenses, living accommodation and a small stipend for loved ones to live in the patient's home. Foster homes are also

financially supported programs for AIDS patients in some communities. In San Francisco, an old hotel was renovated to provide live-in accommodation and a supervised program for AIDS drug addicts.

Figures 15, 16, 17 and 18 illustrate the "matrix" of interconnections possible and the necessity for collaboration and coordination in developing an effective AIDS care program. These diagrams show the movement from home to hospital, or the use of respite bed, and finally the location of death.

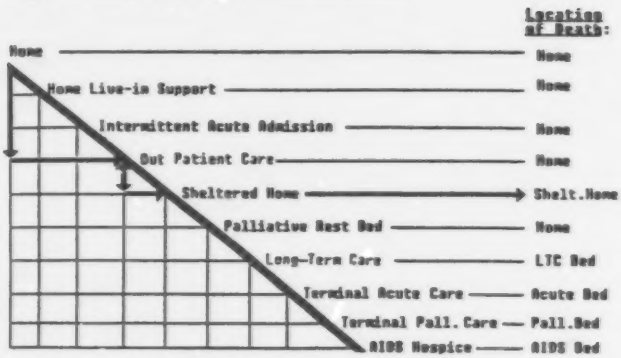
Figure 15: Death in Hospital



This diagram illustrates the present usual route of care. The patient resides at home and is admitted to an acute care bed for problems which arise, likely for treatment of an infection or control of physical symptoms.

When the patient's ability to live at home diminishes, a final admission to an acute bed is arranged. The patient's location of care is Home, Acute Bed, Death.

Figure 16: Death in Sheltered Home

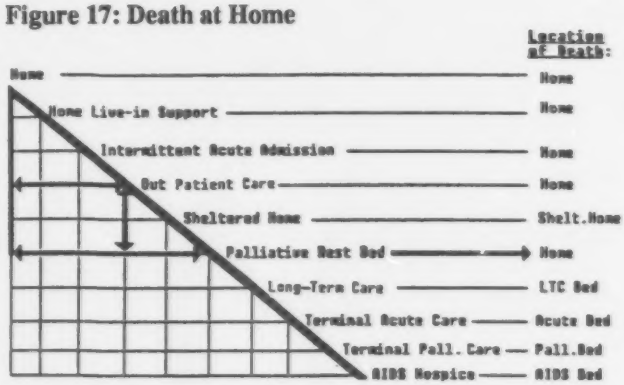


In this example, there are two additional services. The patient remains at home as long as possible. Follow-up care is through a hospital outpatient program.

When living alone becomes impossible, patient moves to a sheltered home, perhaps similar to the Shanti program in San Francisco. Patient continues to be followed through outpatient department (OPD). Death occurs in Sheltered Home.

Location of care is Home, OPD, Sheltered Home, Death.

Figure 17: Death at Home

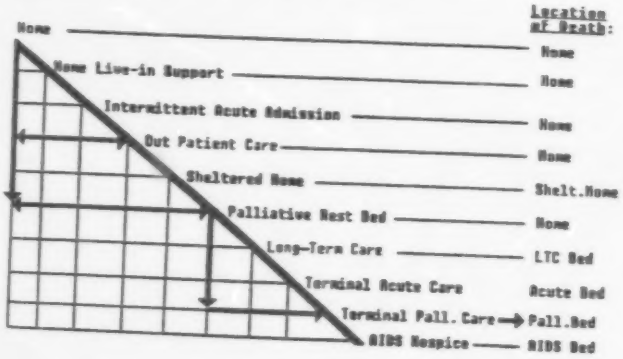


This example may occur where there is a palliative care program which includes AIDS care. Care is supported at home. The hospital OPD provides close follow-up care. An occasional respite bed into the palliative care program beds supports further care at home. Death is at home.

This model necessitates a palliative care program which has both a home program and a palliative care unit.

Location of care is Home, OPD, Respite Bed, Home, Death.

Figure 18: Death in Hospice Bed



This example uses the patient's home, acute bed, out-patient program, respite bed and terminal palliative bed.

Either little home support is available in this case, or there are serious problems which limit home support. One example may be progressive dementia or severe diarrhea.

The location of care is Home, Acute Bed, Home, OPD, Respite Bed, Resident, Death.

After an overall plan of care has been drawn up, a schematic representation of the necessary links in care or an alternative, can be used to establish specific programs, transportation needs, the role of professional and volunteer caregivers, and communication mechanisms among home, hospital and palliative support services.

Finally, in determining the location of care, it is important to consider whether care is established to facilitate death at home or to facilitate care at home until admission is necessary. These approaches require somewhat different support mechanisms and coordination links. For example, if death is to occur at home, very precise support and physical services are essential, including regular home physician visits. Control of symptoms is critical to proper care at home, death will not occur at home if symptoms are out of control and remain that way. Also, if death is impossible at home, then coordinated admission to a palliative care unit or hospital program is important.

In conclusion, home is both the location and the atmosphere in which a patient feels "at home," wherever that may be. There are many possible program supports which could be developed in any one community to provide good care. Collaborative planning, effective coordination and communication, and evaluation of care will result in excellent programs of care when combined with sufficient funding for implementation.

Appendix VI

An Example of A Model of Care

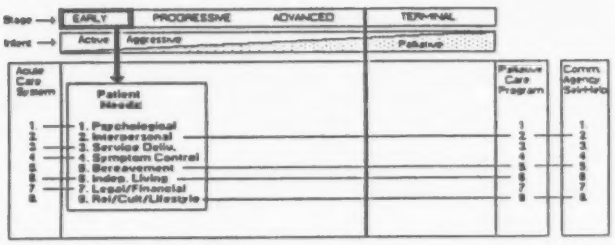
Any Model of Care must include the following eight areas of need outlined in Section 3.2.3 of the report:

1. Psychological Support
2. Interpersonal Relations
3. Service Delivery
4. Symptom Control
5. Bereavement
6. Independent Living
7. Legal and Financial Issues
8. Lifestyle/Cultural/Ethnic/Religious Considerations.

Using the general model as described in Section 3.2, a number of scenarios may be developed by communities, depending on their resources, as they formulate a plan of care. For example, Figure 19 demonstrates the interconnection that might be appropriate for the **Early Stage** of AIDS. In this particular diagram, much of the care is provided through the acute care system, primarily the hospital.

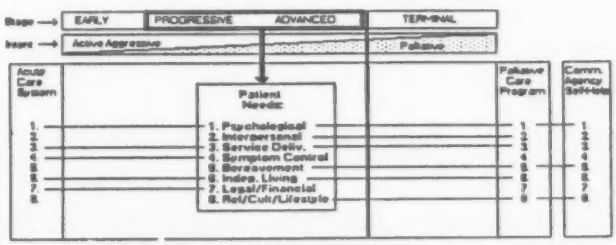
In a large community, care includes medical and nursing care for symptom control (#4), along with the social worker arranging for financial and legal needs (#7). Individual counselling and support (#1) is provided by the social worker and the nurse. Furthermore, the social worker, nurse and home care coordinators assist in arranging home support services (#3). Independent living (#6), while in hospital, is promoted by allowing the individual choices and by having flexible rules. Independence is further supported through an AIDS outpatient clinic with occasional acute bed admissions as necessary. The community self-help group(s) can provide emotional support and counselling (#2, 8). This "acute care program" is primarily hospital-based, but uses other resources. Many combinations are possible.

Figure 19: Early Stage



As AIDS progresses into the **Advanced Stage**, further shifting in responsibility for care may occur. This movement is illustrated in Figure 20 where referral to a palliative care program has occurred. Again, specialized medical and nursing care is provided for symptom control (#4) and also the availability of perhaps a palliative care unit for respite care (#3), thereby reducing pressure on acute care beds. The hospital provides significant care (#1, 3, 4, 6 and 7) and the community services of home care and volunteer support groups continue (#2 and 8).

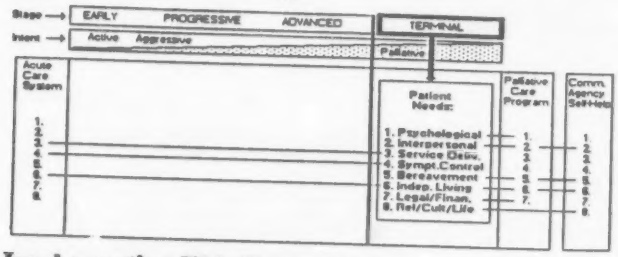
Figure 20: Advanced Stage



In the **Terminal Stage** of AIDS, the threads now move even further. In this example, Figure 21, the palliative care program has now assumed primary responsibility in several areas (#1, 2, 5, 6 and 7) with many of these needs met in the community setting. Some contact with the acute care hospital remains for any needed investigations or active treatments. The patient may be at home

with both palliative programs and home care support, or perhaps admitted to a palliative care unit or hospice. Emotional and practical support (#2, 5, 6 and 8) continues through the AIDS support group and/or nurse and/or social worker and/or clergy.

Figure 21: Terminal Stage



Implementing This Example

To carry out this program example, the care delivery model of Section 3.3 must be included. Using the above example, the Planning Level (see Section 3.3) determines the particular needs of this community. Then the Coordinating Level draws together the threads of the plan, as shown in Figures 19, 20 and 21, into a comprehensive and coordinated plan of action. Obviously, much communication with the Care Level is essential to establish specific roles as well as the limits of individual programs. The Coordinating Level seeks necessary additional funding to meet the needs of the Care Level and then monitors cost-effectiveness and overall use of resources. The Planning Level continues to assess the community's needs from a broad perspective and makes recommendations to the Coordinating Level if the needs and dynamics of the local AIDS situation change. Governments (municipal and provincial) communicate with both Planning and Coordinating Levels to evaluate the local community's program and its potential benefit to other areas of the province or territory.

Summary

This section demonstrates only one specific example of a care model. Depending on the size of the community, the available resources and the number of persons with AIDS, the model of care will vary. Creative use of human resources, both professional and volunteer, is essential to meeting individualized needs. It should be noted that psychosocial support is required of all caregivers including the family physician, nurse, social worker, volunteer, clergy, friends and family.

Because of the need for the many threads connecting the various care systems, it is recommended that one person be designated as Coordinator of Care by the Coordinating Level. This arrangement will facilitate more effective collaboration and communication among all caregivers. This person may be the social worker, nurse or family physician.

Appendix VII

Glossary

Acute care
Care that includes active investigation and treatment with the aim of remission, cure and restoration of well-being.

AIDS
An acronym for Acquired Immunodeficiency Syndrome. According to the Laboratory Centre for Disease Control (LCDC), a case of AIDS is defined as a clinical diagnosis of at least one of the specific infectious diseases or cancers associated with AIDS.

AIDS support groups
Organizations providing care and support to HIV-infected individuals.

Candida albicans
A yeast-like organism which is the causative agent for candidiasis. Oral infections are commonly called thrush.

Caregiver
A provider of care who is either a professional, para-professional or volunteer. Includes physicians, nurses, social workers, homemakers, volunteer visitors and so on.

Chronic care
Care that includes maintaining a level of well-being and independence in an individual with a long-term illness. This care does not fully restore function or well-being and is not curative.

Cryptococcus
A fungus which causes infection of the skin, lungs and gastro-intestinal tract.

Cryptosporidium
A protozoan parasite which causes severe diarrhea that can lead to dehydration and malnutrition.

Cytomegalovirus
A virus of the herpes family which causes illnesses varying from flu-like infections to hepatitis, pneumonia and infections of the brain. Commonly referred to as CMV.

Family
Broadly used to include family of origin, friends and lovers.

Health care professionals
All professionals involved in health care delivery: physicians, nurses, social workers, physiotherapists and so on.

HIV
An acronym for Human Immunodeficiency Virus. A member of the retrovirus family and the causative agent for AIDS.

Inpatient care
Care given while an individual is institutionalized.

Intravenous
Directly into the bloodstream. Often referred to as I.V.

Kaposi's sarcoma
A tumor of the blood vessel walls which appears as purple lesions on the skin. In person less than 60 years of age, this sarcoma is most commonly associated with AIDS. Frequently referred to as KS.

Loved ones
Family of origin, friends and lovers.

Lymphoma
A cancer of the lymphoid tissue.

Mycobacterium avium-intracellulare
A bacterium related to the organism that causes tuberculosis.

Outpatient care
Care given to an individual who lives outside the hospital or institution and comes into a clinic for treatment and care.

Palliative care
The active, compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure or prolongation of life and when the control of symptoms -- physical, emotional and spiritual -- is paramount. It is a multi-disciplinary approach that encompasses the patient, the family and the community. Also referred to as hospice care or care for the terminally ill. (Definition used by the Palliative Care Foundation)

Pneumocystis carinii Pneumonia
A severe form of pneumonia caused by the parasite *Pneumocystis carinii*. It is the most common opportunistic infection associated with AIDS. Frequently referred to as PCP.

Provider groups
Formal organizations which provide care; also includes self-help groups.

Toxoplasma gondii
A protozoan parasite which causes pneumonia, inflammation of the kidneys and skin rashes.

Appendix VIII

Bibliography

Through the Federal Centre for AIDS and Health and Welfare Canada, the Working Group commissioned the Palliative Care Foundation to prepare a bibliography. This document was completed and published in April 1987. The full bibliography is attached to this report and is entitled:

PALLIATIVE CARE FOR PERSONS WITH AIDS:
A SELECTED BIBLIOGRAPHY

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